

DEMOS

THE INTERNET AND END OF LIFE

CIARAN CUMMINS
ELLEN JUDSON
JOSH SMITH

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The Art of Dying Well



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15 Whitehall, London, SW1A 2DD
T: 020 3878 3955
hello@demos.co.uk
www.demos.co.uk

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EXECUTIVE SUMMARY

From small chatrooms where users speak in relative anonymity to huge social media platforms with the potential to reach millions, online conversations about death and dying are many and diverse.

For many, the end of life may be a time of uncertainty and loneliness, and online spaces provide an opportunity to find support. Here, people can share difficult emotions with others who understand their experiences, benefit from repositories of collective knowledge, and feel part of a community of solidarity.

The role played by online forums has grown since the onset of the Covid-19 pandemic, as suddenly people have been unable to access offline services or in-person support, and organisations have shifted to providing services online. Even after the immediate crisis of the pandemic is past, it is likely that this shift towards digital communication and engagement will remain and so a greater understanding of the role online spaces can best play in supporting people at the end of life is crucial.

This project aims to listen to and bring into the policy debate the voices of the dying, those who accompany the dying, and those who have been bereaved: to support a greater understanding of what those in the last stages of life, and those caring for them, need, and how this can best be provided, both online and offline.

We collected over 110,000 posts from public online forums where people were discussing issues relating to death, dying and end of life care. Dating from 2003 to 2020, across 7 public forums and social media platforms, we identified five key themes emerging from people's discussions in these spaces to explore further:

- Grief: conversations centering around grief and bereavement
- Care: people's experiences of being carers or being cared for

- Existential: discussion of existential beliefs about life and death
- Online forums: discussion of the online forums themselves and the role that they play in people's lives
- Animals: conversations around grieving of, or the support offered by, pets.

We then analysed these to draw out insights about how people are using and relying on online spaces, before discussing the findings to inform our policy recommendations with policy experts and practitioners working to support people at the end of life or those who are grieving.

We found that online spaces are supporting people in three key ways: providing comfort and validation from others going through similar experiences; enabling users to build their own capabilities, by building their understanding and access to information about end of life; and acting as a space where communities can develop, that people can come back to time and again to support others and be supported themselves.

Our key findings, from both our data analysis and our consultation workshops, were:

ONLINE SPACES ARE A CRUCIAL CORNERSTONE OF SUPPORT FOR PEOPLE AROUND THE END OF LIFE, PROVIDING VALUABLE ACCESS TO PEER-TO-PEER SUPPORT

They provide a unique way of enabling people to communicate with others who have similar experiences to their own: to seek comfort, advice and validation when they are unable to find it from

other sources, and to express themselves freely, without judgement or constraint. People care about these spaces - they invest in and help to build these online communities. They can help to alleviate loneliness and isolation, and can provide support over a long period of time. Workshop discussions highlighted how they enable people to speak in relative anonymity to other users and with privacy from their offline support networks. They are open to all to access, without having to meet certain criteria in order to benefit from support. They cross geographic boundaries and mean that people can more easily access support wherever they are, at any time of day or night.

"The joy of it is the democracy of it, you can reach so many people".¹

ONLINE SPACES SUPPORT BETTER KNOWLEDGE AND UNDERSTANDING

People are able to access these spaces to share knowledge and advice, which itself can turn into a longstanding resource for others to use. People in unfamiliar situations, such as being new carers; those who want to discuss issues that are deeply personal, sensitive or difficult to speak about elsewhere online or off - they can use online forums as a place to speak and to be spoken with.

But discussions in our workshops highlighted that many people, though they might benefit from engaging in an online forum, would not know where to go to find one that specifically meets their needs, and is a safe place for them to engage. Moreover, existing services and practitioners supporting people at the end of life may not know what forums exist, what needs they serve, and what they can safely recommend to their patients or clients. There is a clear need for greater signposting of the services and resources that exist, within healthcare settings and outside of formal support services.

THERE ARE BARRIERS TO PEOPLE ENGAGING IN THESE ONLINE SPACES

Participants in our workshops raised how many people they support would not have the digital skills or confidence to engage in online forums. With 10% of the UK adult population in 2018 an internet non-user², and older age groups, who may particularly need support around end of life care, particularly affected by digital exclusion.

As well as digital skills, there are other barriers to engaging in online spaces, such as limited access to devices or to inconsistent internet access, which disproportionately affects certain groups. It is not only users, as well: staff who offer support services may themselves not be confident running and monitoring an online forum.

ONLINE SPACES ARE PLACES WHERE PEOPLE ARE ABLE TO RAISE CONCERNS AND FRUSTRATIONS - BUT NOT SOLVE - FAILINGS IN HEALTH AND CARE SERVICES

This research finds that online spaces cannot be the only option available to people - nor can they solve wider problems by themselves. There is value in people being able to share their experiences with others: but as important as this emotional and practical support is, this highlights that the current systems within health and care services around the end of life are not working for everyone: that some people feel disempowered, not listened to, and are struggling to navigate the system effectively.

MOREOVER, ONLINE SPACES MAY NOT BE SUITABLE FOR ALL GROUPS, NOR ABLE TO MEET EVERYONE'S NEEDS

People who are particularly vulnerable or with complex needs may need more consistent and expert support than a peer forum can provide. Also highlighted throughout our workshops was that others - and practitioners also - may simply prefer and respond better to in-person or telephone forms of support, or a combination. Furthermore, cultural and social factors, such as language and age, can affect what kind of space people need or want. There is a need for a diversity of forms of support to be developed and maintained to enable people around the end of life to be able to make informed choices about the kinds of support they need and how to access it. Though this project has identified how people speak within forums about their experiences, there is more to be learnt about the effect of engaging in these forums on people's wellbeing overall.

¹ Mandie Howard, in our workshops

² ONS. Exploring the UK's digital divide. 2019. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04#the-scale-of-digital-exclusion-in-the-uk> [date accessed: 07/05/21]

RECOMMENDATIONS

There is a need to better integrate online forums into support around the end of life. This integration has three key pillars:

- to **build presence**, increasing knowledge and awareness of online forums and their role both amongst users and practitioners e.g. through increased signposting;
- to **support access** and enable people who would benefit from online forums to engage with them, tackling digital exclusion and building digital capabilities amongst users and practitioners;
- to **improve practice**, through strengthening the evidence base about what role online services are best suited for in support provision and how to make them safer spaces.

Below we detail how these pillars point the way to both immediate recommendations for how existing support could be improved, and a longer-term model for how online support could form a part of end of life care.³

IMPROVING EXISTING SUPPORT

Recommendation 1: Government (including DCMS and DHSC) should invest in addressing the digital divide, and support both users and providers to better engage with online services.

This should be achieved through:

- The creation of a Minimum Digital Living Standard: a 'universally recognised baseline for what it means to be digitally included in the UK'.⁴
- Supporting community organisations that help people at risk of digital exclusion
- Investing in digital infrastructure in less well-connected areas.
- Supporting organisations providing services to people at the end of life to upskill staff digital

skills. For instance, where forum moderators are employed, these should be people with a mix of digital skills and training in end of life care, mental health and safeguarding.

Recommendation 2: Health services and practitioners should continue to develop hybrid models of end of life support post-pandemic, including online, telephone and in-person support, to facilitate greater patient choice and access to a wider diversity of forms of support.

Where new online systems have been set up through the pandemic, these should be retained but will need 'reorienting' to ensure they are continuing to meet people's needs and meet the same standards as offline services offered.^{5, 6}

Recommendation 3: Organisations which provide online forums should clearly signpost key information about the forum and what it offers to users, and what alternatives are available.

This information should include what their purpose, guidelines and policies on moderation are, how users can be supported to engage in the forum if they are at risk of exclusion and signpost users who may need support beyond what that forum can offer to other forums or resources.

Recommendation 4: In developing online forums, organisations supporting people at the end of life should ensure there are options tailored to support specific communities at greater risk of exclusion from accessing online services - for instance, people who primarily speak languages other than English.

These should be created in collaboration with the relevant communities and mechanisms should be put in place to ensure these forums continue to attend to the risk of exclusion in the future.

³ With thanks to participants at our workshops for helping develop these points.

⁴ Bowyer, G. Grant, A. and White D. Learning From Lockdown: 12 Steps To Eliminate Digital Exclusion. Carnegie UK Trust. 2020. Available at: <https://www.carnegieuktrust.org.uk/blog/learning-from-lockdown-12-steps-to-eliminate-digital-exclusion/> [date accessed: 07/05/21]

⁵ Horton, T. Hardie, T. Mahadeva, S. Warburton, W. Securing a positive health care technology legacy from COVID-19. The Health Foundation. 2021. Available at: <http://health.org.uk/publications/long-reads/securing-a-positive-health-care-technology-legacy-from-covid-19> [date accessed: 07/05/21]

⁶ Covid-19 Committee. Beyond Digital: Planning for a Hybrid World. House of Lords. 2021. Available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldcvid19/263/263.pdf> [date accessed: 07/05/21]

Recommendation 5: Health services and local authorities (e.g. through a mechanism like ICS Health and Care Partnerships⁷) should engage with organisations who provide online forum support to identify where there are common complaints of systematic failures that could be addressed.

Moderators of these forums should also be empowered to signpost people who raise these issues within forums to official routes or provide support for raising their grievances if desired.

Recommendation 6: The role of animals and pets in end of life care and companionship should be more widely recognised.

Care homes, hospitals and hospices should facilitate visits, working together with families as well as organisations that provide pets as therapy, to better support people at the end of life.

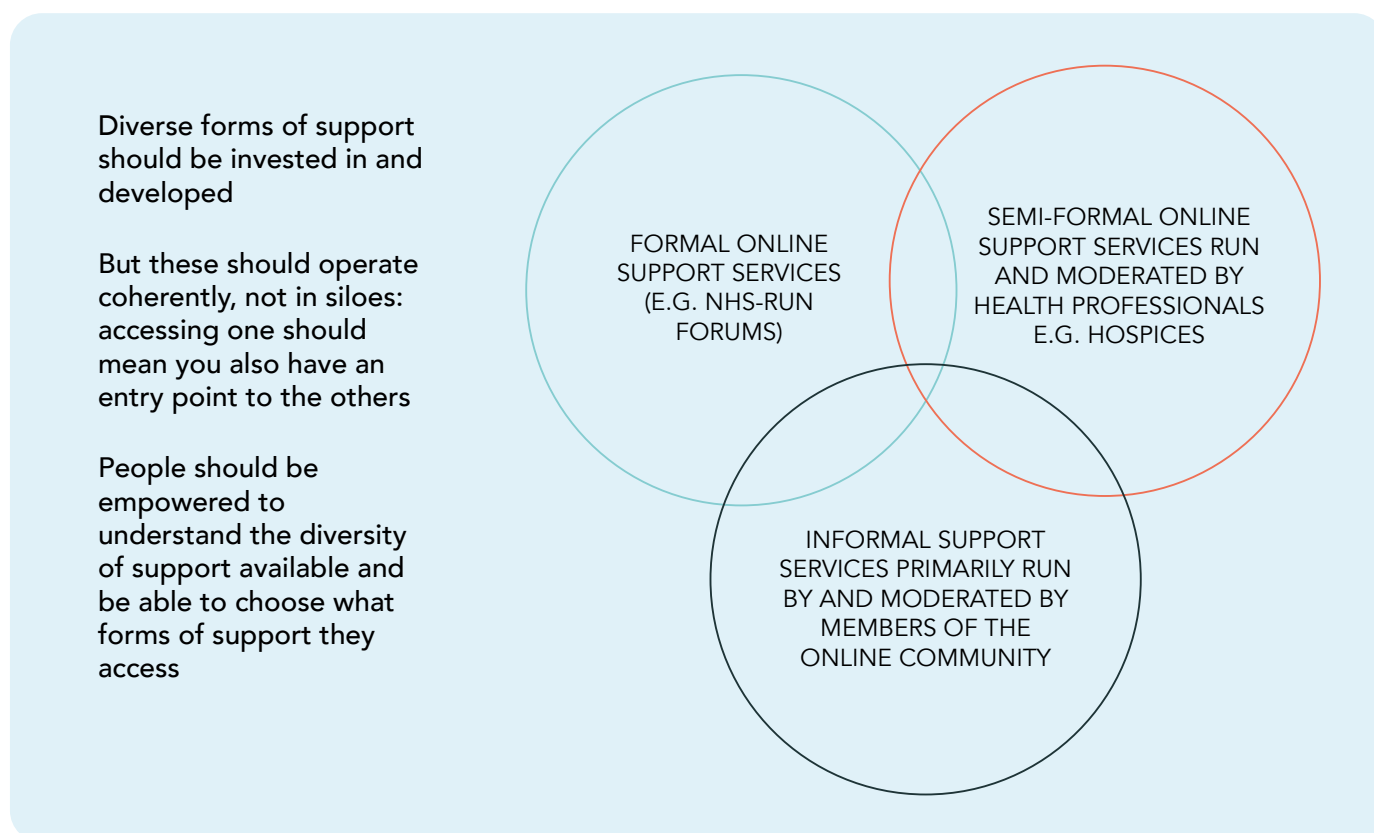
A NEW MODEL FOR COORDINATING ONLINE SUPPORT

Recommendation 7: Leading organisations providing support and care at the end of life, those providing online forums, and tech companies should work together with the NHS to create a shared database of online forums supporting people at the end of life, with details about who they are for and how to access them.

This should be publicly searchable, and signposted across the spectrum of forums: it should be available to healthcare professionals to enable them to direct patients, moderators of forums so they are able to direct users to other forms of online support if needed, and tech companies to facilitate better automated signposting of support services to users of online platforms. This should include a wide range of forums from informal to formal, and covering a diversity of types of platform aimed at different audiences. This would enable people to engage with a variety of forms of support, from whichever point they had entered the support ecosystem.

FIGURE 1

HOW CAN ONLINE PEER-TO-PEER SUPPORT BE INTEGRATED INTO HEALTH PROVISION?



7 Department of Health and Social Care. Integration and innovation: working together to improve health and social care for all. UK Government. 2021. Available at: <https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version> [date accessed: 07/05/21]

Recommendation 8: Organisations running forums should establish a mechanism through which they can share their experience and best practice in providing, running and moderating online forums.

This should include representation from a diverse range of forums, including both small community chat rooms, specialised forums managed by healthcare professionals, and large social media platforms to maximise the impact of knowledge sharing.

Recommendation 9: NICE should conduct a review of the evidence specifically of online forum support (as opposed to digital health interventions more broadly) as part of end of life support and care for patients, their families and friends, and carers.⁸

This could include commissioning clinical trials to investigate the outcomes for people's wellbeing and mental health of engaging with different kinds of online support, for people with different needs. This would then provide a knowledge base through which care and support around the end of life could be better tailored to people's individual needs. This could form the basis, if found likely to be effective, of developing forums which are NHS-branded and staffed by mental health professionals, and contribute to the development of clearer guidelines for people seeking support as to what is most likely to help them.

Recommendation 10: NICE should develop a standards framework relating to online forums.

This could build on existing frameworks for using digital technologies and work together with leading organisations providing support and care at the end of life.⁹ These standards could be used to certify that forums relating to end of life care and discussions meet standards of moderation, safeguarding procedures, privacy, and clarity to users identified as necessary through an evidence review (as above). This would enable signposting of forums, such as through a shared database, to be more effective and reliable.

Recommendation 11: Organisations which run community forums which are run by community volunteer moderators should incentivise, reward and support this digital civic labour

Those who engage in community moderation should have clear access to support and resources to help them in moderating and supporting others in a peer-to-peer community group, from guidance on safeguarding to emotional wellbeing support for themselves, and be rewarded for their efforts.

8 O'Donnell, H. Lugton, J. Swenson, C. Pagliari, C. Digital Health Interventions in Palliative Care: A Systematic Meta-Review and Evidence Synthesis. medRxiv. 2020. Available at: <https://www.medrxiv.org/content/10.1101/2020.09.16.20195834v1.full.pdf> [date accessed: 07/05/21]

9 National Institute for Health and Care Excellence. Evidence standards framework for digital health technologies. 2021. Available at: <https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies> [date accessed: 07/05/21]; NHS. Digital Technology Assessment Criteria (DTAC). 2021. Available at: <https://www.nhs.uk/key-tools-and-info/digital-technology-assessment-criteria-dtac/> [date accessed: 07/05/21]

INTRODUCTION

The internet, and the online spaces, online identities, and online communities that are now part of our everyday lives, have brought with them new questions that range from the technical to the existential: from what it is to be connected to the Internet to what it now means to be connected to another person. This has become as true at the end of our lives as it is throughout them.

Things we might hope to find at the end of our lives - companionship, capability, caring - are evolving new meaning in cyberspace.

And how online spaces can help those who are dying, those who accompany them, and those who have been bereaved, has taken on a new significance in recent months. The pandemic has highlighted - though not invented - the crucial role that online spaces play in connecting people throughout their lives, including the end of their lives. These spaces are where people are able to come together - people living with a terminal illness; their loved ones and carers, and those who have been bereaved - on their own terms, to speak freely about their experiences.

In partnership with The Art of Dying Well at St Mary's University, Twickenham, CASM at Demos set out to investigate how people are speaking about death and dying online: in a variety of different kinds of online spaces, with different purposes, rules and norms. We wanted to better understand where these discussions happen; what kind of help people are

looking for; what support they receive; and what they still need, to contribute to the much-needed debate about how to die well and help improve public policy and practice.

These are conversations that often those working in healthcare and to support people at the end of life will not see. We spoke with experts working in these fields who told us of the limitations patients, relatives and carers face: that they want to speak to others who know what they are going through; that they may want spiritual and practical advice or emotional support that healthcare professionals aren't best placed to offer. For many, these are needs that online spaces can help meet - from large social media platforms to small specialised support groups online.

We are well versed in what goes wrong in online spaces - headlines scream the dangers of disinformation, of polarisation and division. These are all real and serious problems. But we must be careful not to overlook the positive spaces that exist: places of comfort, community and connection that can bring strangers together to support each other, sometimes better than anyone else can. It is these spaces that we sought to better understand: to take a snapshot of what role online spaces are playing in people's lives through difficult times, what this means for working towards more positive online experiences throughout people's lives, and, crucially, what we can learn about the wider needs of people who need support at the end of life - themselves, their carers, and their loved ones.

BACKGROUND

What it means to die well is an ongoing question: one which affects every one of us, but one which it has become difficult, even taboo, to talk about. In the 15th century, the *Ars Moriendi* - 'The Art of Dying' - was published, a Christian tract including religious instruction and encouragement for a dying person, their family and companions. The "omnipresence of death in the Middle Ages" meant that it was a necessity for people to engage with the often very present question of what they wanted their death, as well as their life, to be like.¹⁰

In this millenium, we don't have such a manual. Research by Demos, alongside many others, has long highlighted the need for more individualised, person-centred approaches to end of life that enable and empower people to shape their end of life care and experience.¹¹ But there still remain significant gaps between ideal and practice: between the experiences that people most want and need, and the reality of how healthcare is provided and decisions are made about end of life care. And these conversations are still not mainstream: people still struggle to discuss death and dying openly with their family, with their friends, with their doctors, with their patients.

And as life expectancy increases, and with an ageing population, many more people will reach the end of their lives with advanced and more complex needs. In the UK, just under half of the population will die in a hospital, and just under a quarter will die at home, sometimes alone (during the pandemic, hospitals have remained the most common place of death).¹² The burden of mental ill-health, grief and stigma surrounding death and bereavement is causing avoidable distress to those dying (of all ages), to their carers, and to loved ones; that this burden has

a strong social gradient, with the poorest and most vulnerable experiencing the worst impact; and that the health and social care system is increasingly uncomfortable with supporting people around death and dying.¹³

With the onset of the Covid-19 pandemic, new challenges have arisen in how to help people to die well. At a time when people were often most in need of support, in-person support and services had to be suspended; traditional practices such as funerals have been disrupted, and the power that individuals and their families have to shape their end of life experiences has been fundamentally altered by the public health crisis.

However, to understand what people need and want at the end of life - whether they are experiencing a life-limiting illness themselves, caring for someone who is, mourning a loved one who has died, or considering their own mortality - there is a new resource that would have been unimaginable in the Middle Ages: the crowdsourced wisdom that can be found on the Internet. As people's lives move online, so too do discussions about death and dying: online spaces provide a uniquely free context within which people can talk to others that they know or people they have never met about any aspect of the end of life - whether practical, physical, emotional, or spiritual.

By engaging directly with these online discussions, this project aims to listen to and bring into the policy debate the voices of the dying, those who accompany the dying, and those who have been bereaved: to support a greater understanding of what those in the last stages of life, and those caring for them, need, and how this can best be provided, both online and offline.

10 Thomas, S. *Ars moriendi-The Art of Dying*. Bodleian Library. Available at: <http://bav.bodleian.ox.ac.uk/news/ars-moriendi-the-art-of-dying> [date accessed: 07/05/21]; Thornton, K. Phillips, C.B. *Performing the good death: the medieval Ars moriendi and contemporary doctors*. Medical Humanities. 2009. Available at: <https://core.ac.uk/download/pdf/156627909.pdf> [date accessed: 07/05/21]

11 Leadbeater, C. and Garber, J. *Dying For Change*. Demos. 2010. Available at: https://demosuk.wpengine.com/files/Dying_for_change_-_web_-_final_1_.pdf?1289561872; Paget, A. Wood, C. *Ways and Means*. Demos. 2013. Available at: https://demosuk.wpengine.com/files/Ways_and_Means_-_web.pdf?1371658165 [date accessed: 07/05/21]

12 Public Health England. *Palliative and End of Life Care Profiles*. UK Government. 2019. Available at: https://fingertips.phe.org.uk/profile/end-of-life/data#page/0/gid/1938132883/pat/159/par/K02000001/ati/15/are/E92000001/iid/93474/age/1/sex/4/cid/4/tbm/1/page-options/eng-vo-0_0vw-do-0 [date accessed: 07/05/21]; Scobie, S. *Measuring mortality during Covid-19: a Q&A*. Nuffield Trust. 2021. Available at: <https://www.nuffieldtrust.org.uk/news-item/measuring-mortality-during-covid-19-a-q-a> [date accessed: 07/05/21]

13 McManus, J. 2018. *End of life care symposium*. Royal Society of Medicine. Oral presentation.

WHAT IS AN ONLINE FORUM?

We use the term 'online forum' to describe a number of different kinds of online space. The term covers a huge diversity of spaces, built on different infrastructure, with different purposes, and which are run, overseen and used in different ways.

We examined three categories of online space:

	Social media platform	Community forum	Specialised forum
Purpose	Connecting people and facilitating content-sharing across all demographics and topics	Facilitating discussion and advice for a broad demographic across a wide range of topics	Facilitating discussion and support around a specific topic
Structure	Run by large transnational corporations	Run by private companies	Often run by charities as part of their operations
Profile	Very high-reach: tend to be globally known, very high-revenue	High reach, widely known, high-revenue	Smaller reach, likely to be known to specific groups

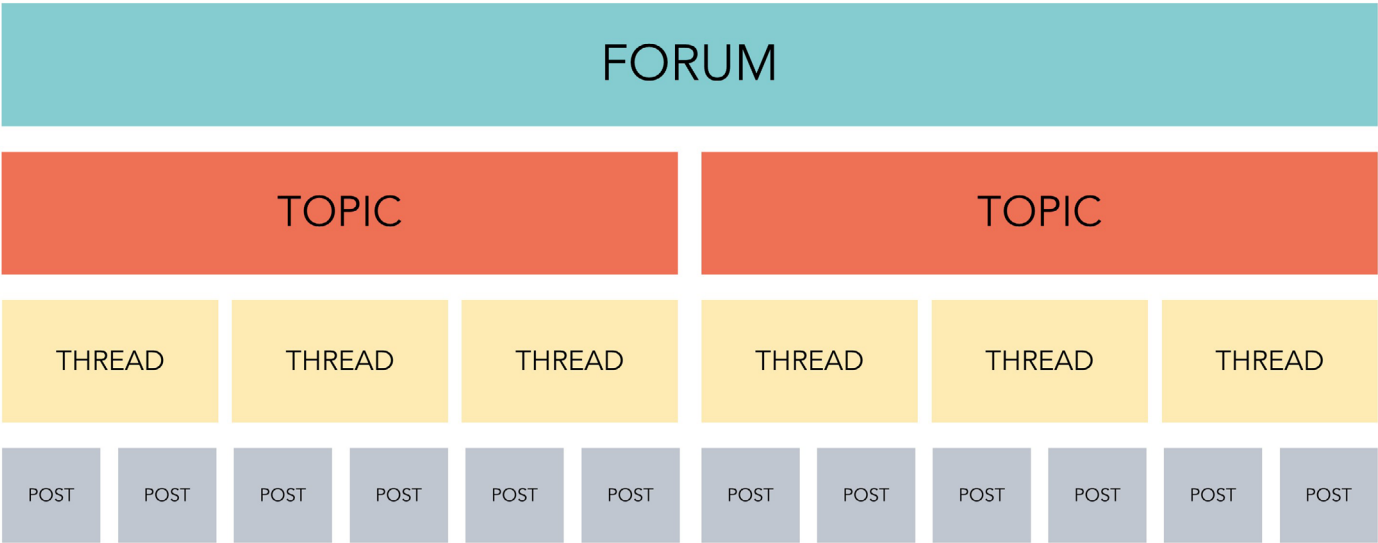
Forums have different rules and guidelines for what content is or is not allowed: illegal content is never allowed, but what other rules are set out or enforced varies hugely: from not allowing offensive language, to not allowing advertising, to not allowing discussion or certain topics or opinions.

Forums have a variety of methods for moderation, and most employ some combination. The primary difference between forums is scale of moderation: a large social media platform will have a toolbox of different automated methods and thousands of human moderators, while a specialised forum may have one or two people whose work includes moderating the forum. Moderators, as well as enforcing rules and removing posts, may be involved in responding to users directly in the forum and in ensuring safeguarding on the site.

- Automated moderation: where posts that include e.g. illegal content may be automatically detected and removed.
- Human moderators: people employed by the company who either proactively review posts to ensure they comply with the rules of the forum, or who reactively review (and remove if needed) in response to user reports of rules violations
- Community moderators: users of a space, not employed by the company who proactively or reactively review/remove posts. Sometimes the rules enforced by community moderators may be stricter than the company rules (e.g. a community may decide they want to prohibit discussion of a particular topic in a subgroup for irrelevance, though it may be discussed elsewhere on the forum).

How conversations are curated - how users locate and navigate through different conversations and how they contribute to them also varies. Conversations are usually searchable, and some forums use hashtags to identify conversations on a similar topic. A common structure is as follows: where various topics are set by the forum for discussion, to which users can then start their own conversations or 'threads', to which others can reply with their own posts.

FIGURE 2
COMMON STRUCTURE OF ONLINE FORUM DISCUSSIONS



Other 'online spaces' other than forums would include Zoom calls, such as Zoom support groups; WhatsApp groups; closed Facebook groups; or 1-2-1 'live chat' functions with organisations or support services. These, as more private spaces for individual conversation, were out of scope in our research - though some discussion within the online forums we examined reflected on people's experiences in other online spaces.

METHODS

This project explores how people use online spaces to talk about death and dying, and what we can learn from this about what support people need and how this can best be facilitated, online and offline.

Our data collection and data analysis was carried out using Method52, a suite of tools for collecting and analysing large free-text datasets developed by Demos in partnership with the University of Sussex. We also carried out interviews with a range of experts in the topics of death and dying.

We then ran two workshops with experts, including academics and practitioners who work to support people at the end of life, such as those working in hospices or who provide counselling to those at the end of life. These workshops discussed what online spaces were most useful for; what the barriers to engaging in them were; what problems there could arise with supporting people online; and what other forms of support were needed. We then carried out two workshops with policy experts to help develop and refine our recommendations, discussing what the findings meant for policy and practice in the UK.

These discussions formed the basis for the policy recommendations presented in this report.

ONLINE SPACES

This project aimed to examine conversations about death and dying across a range of different online spaces. The forums we selected to examine were identified through searches of mainstream social media for relevant sub-forums and sub-communities, searches to identify specialist forums focusing on end of life, and through consultation with experts.

Key details of forums were analysed to determine if the forum was appropriate for analysis. Crucial in determining which forums were selected (as judged by analysts) were: relevance of content of a forum to the research questions; likelihood of discussion which used terms such as 'dying' which was not relevant to the research questions; the privacy of the space; and if there were significant safeguarding risks.

In selecting the forums, we selected only data which was public to examine. Our definition of what constituted 'public' data was not only data which was accessible to us technically: but based on our assessment of the features which our report A Room of One's Own found were important to the public in defining a space as public or private:

- Forums we examined must have been able to be located through search engines
- Data we collected must be accessible to anyone without logging in or making a profile
- Data we collected must be accessible to anyone without an invitation.
- Where a site was configured to ask automated data collections not to access it, (this is often specified in a file called 'robots.txt'), these requests were obeyed.¹⁴

Other features which we took into consideration were:

- The size of the space: the larger the space, the more 'public'
- The rules of the forum.

In the interests of maintaining privacy, we are not publishing the names of the forums we examined, but examined a range of platforms we have grouped as:

- 'social media' - high-profile, high-reach platforms which include discussion of a variety of topics
- 'community forums' - traditional internet chatroom/message board-type spaces, which are geared at engaging particular groups of people with shared interests
- 'specialised forums' - similar in technical setup to the community forums, but specifically geared towards a discussion of issues related to death and dying - living with a life-limiting illness, caring for someone with a life-limiting illness, and dealing with bereavement.

Often these forums encompass discussion across a wide range of topics, so we narrowed our collection of data to specific parts of each forum that were

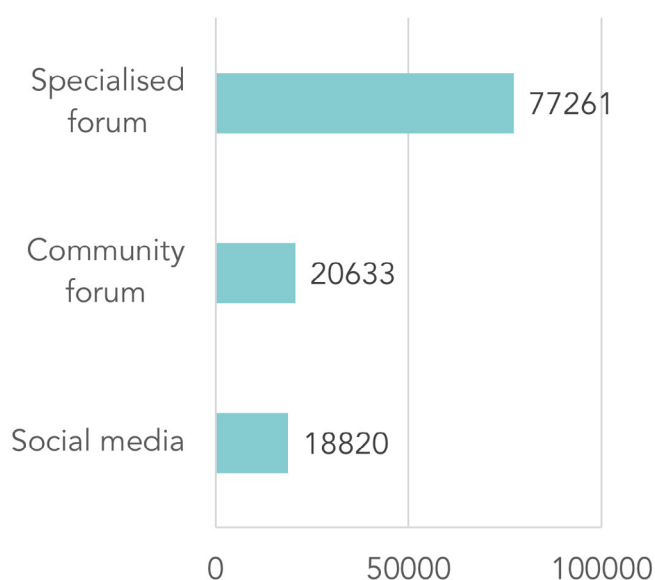
14 Judson, E. and Smith, J. A Room of One's Own. Demos, 2020. Available at: <https://demos.co.uk/project/a-room-of-ones-own-a-guide-to-private-spaces-online/> [date accessed:01.04.2021]

most likely to be relevant (such as a particular page dedicated to issues around death and dying).

We collected 116,748 posts from 7 forums: 2 social media, 2 community forums and 3 specialised forums. To collect posts, we used Method52 to request the contents of discussion threads on each site, using a process sometimes referred to as 'web scraping.' This works in much the same ways as a web browser would - but instead of using the returned text to display a web page, our program saves the response to a database. The program then follows links on the seed page which lead to specific parts of the site - in our case specific forums concerning death.

The dates of the data collected spanned from May 2003 to September 2020 (these dates were across the whole dataset, and data collected from each forum was from a subset of this timeframe). On collection, and before data analysis, the data was anonymised as far as possible, by removing metadata related to the comment likely to be usable to identify its author, including social and site usernames and mentions, images and originating URLs. During coding, only the text of the posts was available to analysts.

FIGURE 3
DISTRIBUTION OF POSTS ACROSS ONLINE FORUMS BY TYPE



VOLUME OVER TIME

Data collected was over a long period of time, but with a clear general increase over time, to be expected with increasing digitalisation and the increasing number and familiarity of online platforms.¹⁵ Volume of posts increased around 2020, likely due to the Covid-19 pandemic. The pandemic has meant that many more people have been suddenly affected by serious illness and loss, while people's access to support and information has simultaneously been disrupted and in many cases moved online. Whether the pandemic was a peak in online support for issues relating to death and dying is hard to say, though a complete future reversal is unlikely. Demos' Build Back Stronger report found 75% of people would prefer essential services, including healthcare, to be accessible both online and offline after the pandemic, even if it is more expensive.¹⁶ A desire for choice came through in our workshops with practitioners too. Some were enthusiastic about carrying on with digital services, some felt these were only stand-ins for face-to-face support, and some placed themselves in between.

IDENTIFYING THEMES

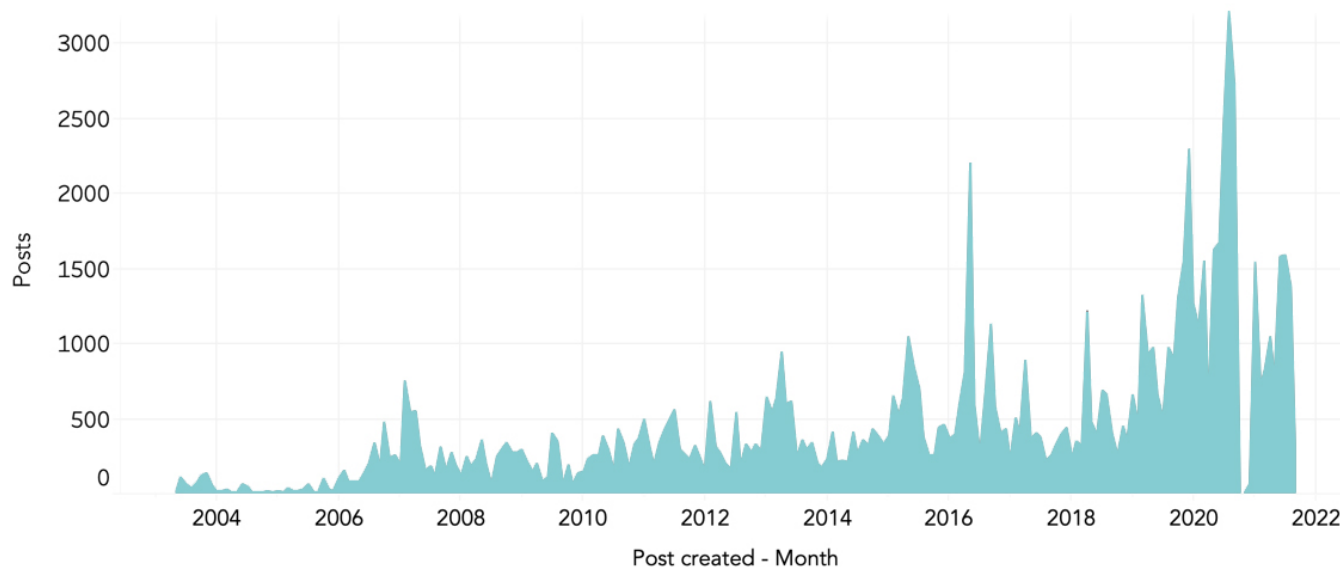
We also sought to filter our dataset to remove content which was posted by users who were under 18, while recognising that although important this was not possible to do completely. We tested a range of keywords and phrases with a sample of the data, which would indicate a user was under 18 to see which returned true positives, and those which returned results were then used as filters and applied to the rest of the data. We then carried out a re-filtering of the data upon finding more key phrases within posts we were examining which indicated the user was under-18.

Below, we present a thematic analysis of themes present in the dataset - the discussions which were in fact taking place around death online. To discover these themes, we used a Natural Language Processing (NLP) technique which can help discover characteristic terms, phrases and discussions within large, human datasets of the sort analysed here.

¹⁵ For context, the 4 social media platforms currently most popular in the UK (<https://yougov.co.uk/ratings/technology/popularity/social-networks/all>) were launched as follows: Facebook in 2004; Twitter in 2006; Instagram and Pinterest in 2010.

¹⁶ Demos. Build Back Stronger. 2021. Available at: <https://demos.co.uk/wp-content/uploads/2021/03/Build-Back-Stronger.pdf>. P.19. [date accessed: 07/05/21]

FIGURE 4
VOLUME OF POSTS ACROSS TIME



CLUSTERING

Clustering is a technique by which an algorithm is used to determine where words commonly co-occur within a dataset, presenting analysts with lists of terms which regularly appear together. Where a group of posts on a given topic often contain similar words - for example, 'Jesus', 'Lord' and 'prayer' in conversations around religion - these may appear in a cluster. This is often a chaotic process, but can be useful in determining the broad topics which are likely to be under discussion in a large dataset, without having to randomly sample and read the posts themselves.

Through these processes we identified five themes of particular interest:

These themes were:

- Grief: how are people expressing grief online?
- Care: how are people talking about their experience of care and health services?
- Existential: how are people talking about the nature of life and of death?
- Animals: how are people discussing animals (particularly pets) online?
- Online Forums: how are people discussing the forums themselves?

These themes represent a snapshot of discussions taking place online around the end of life, rather than a comprehensive overview of everything being

discussed: these were themes which came out through the clustering analysis and were of particular interest for the research questions.

To explore these themes within the data, our primary method was using keyword filters so that posts containing a term which was likely relevant to the overall theme, and then training NLP classifiers to identify posts which were in fact relevant to the theme.

NLP classification complements the discovery processes described above, and goes one step further - by allowing those discovered themes to be explored in much finer detail, again without resorting to manual analysis of random samples from a large dataset. Classifiers can be trained to make complex distinctions within large datasets; they are essentially algorithms which, at their best, can be used to make a distinction within the data which you would usually need a human being to make. For example: does a post which uses the phrase "I'm dying" concern the act of dying, or an expression of amusement?

These classifiers are bespoke - they are trained by analysts on documents from this dataset. During training, the performance of each classifier is measured against a 'gold standard' of documents labelled by humans, allowing us to measure accuracy in each specific case. These levels of accuracy varied across themes, and reflecting the various levels of complexity in the decisions we were attempting to make. An advantage of this method is that in the process of building the classifier an analyst interacts with the data and so is able to reflect on themes and nuances which are arising within a dataset.

Theme	Definition	Accuracy: Classifier 1	Size of Dataset 1	Accuracy: Classifier 2	Size of Dataset 2
Grief	Experiences of grief and offers of condolence where they likewise discuss personal experiences, focusing in the second classifier on users who explicitly reference having nowhere else to turn to to discuss their experiences.	0.610	55,275	0.735	733
Care	Personal experiences of the care system, focusing in the second classifier on users who explicitly reference turning to online spaces as they feel they aren't being listened to elsewhere.	0.620	14,349	0.720	2,756
Existential	People writing about what there is after death: philosophical musings on consciousness, experiences with ghosts/spirits, hopes or fears about if there is anything after death, discussion of religious beliefs like heaven or hell.	0.827	1,392	N/A	N/A
Animals	Personal experiences with pets in relation to death (i.e. their deaths or their being companions during grief).	0.723	1,872	N/A	N/A
Online Forums	Discussion of the online spaces being used that relates to discussion of the forum and on interactions within the forum, particularly relating to gratitude (e.g. 'thank you for posting').	N/A	295	N/A	N/A

The Animals and Existential classifiers (see table below) were relatively straightforward to train. For more complex decisions, such as whether or not a post was an expression of grief, we found that automated classification was not able to determine to a high enough degree of accuracy whether posts fell into these nuanced categories. In these cases, we took an alternative approach: we examined the Grief and Care data through an iterative approach of classification and keyword annotation to identify sub-themes that were specific enough to classify on. In the first iteration of both, we attempted to hone in on references to personal experiences to ensure we were hearing the voices of the dying, those who accompany the dying, and those who have been bereaved. In each case, discussions were rich, varied and complex. Discussions of grief ranged from users discussing experiences such as anticipatory grief (grief felt before someone has died), to how grief had affected a friend's political views, or differing opinions on grieving card messages. Discussions of care ranged from agency carers complaining about administrative staff, people comparing experiences of private and local authority care, or discussions of the advantages and disadvantages of particular

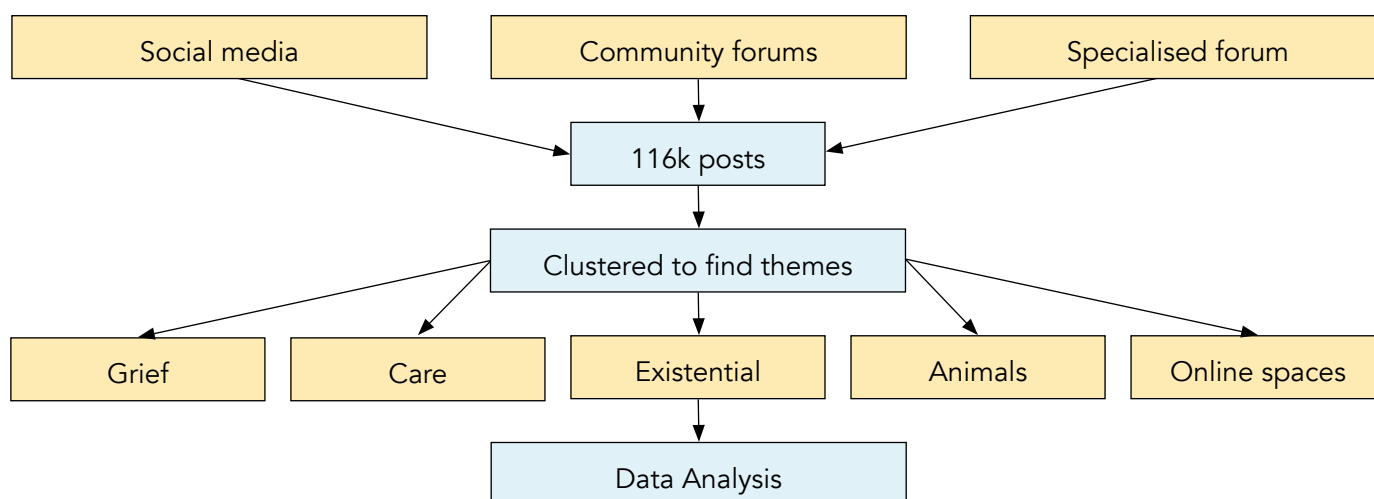
surgical treatments. What stood out across the Care and Grief subsets, however, was a sense of not being listened to elsewhere or of having nowhere else to turn to to be heard and supported. This more precise category of experiences therefore was used to annotate and classify data in the second iteration of the Care and Grief themes.

The Online Forum dataset we established through an iterative process of using keyword filters to examine the data: we specifically focused on where people were expressing gratitude towards others within the context of interacting with other people in a forum, to enable us to draw out what was positive about these spaces.

DATA ANALYSIS

Where datasets were small enough we analysed these qualitatively to draw out themes and insights. Where datasets were larger, we combined clustering analysis with surprising word analysis to identify themes within each dataset, along with insights gained from the classification of the data. This analysis forms the basis for this report.

FIGURE 5
OUTLINE OF DATA COLLECTION AND ANALYSIS



SURPRISING PHRASE DETECTION

A process by which a ‘foreground’ dataset (in our case, posts made on a relevant forum) is compared to a large ‘background’ dataset (we used the entire of Wikipedia’s English language section). This background data is used to establish how often words should be expected to appear. Words appearing in the foreground data are then ranked according to how ‘surprising’ they are; how much more often they appear than we might expect them to. The most surprising words or phrases are then presented to an analyst, and those which seem like they might belong to a coherent theme are used to search the dataset to find matching posts.

LIMITATIONS

As we studied only a selection of online forums, and within that, did not explore in full all of the themes emerging, this report presents a snapshot of the wider discussion of death and dying online. In particular, for the protection of privacy, we did not examine forums on which we judged users had a reasonable expectation of privacy (such as closed groups). The nature of conversations about death and dying may take different shapes in such private settings, given the differing social norms that apply. However, it is our observation that the level of detail about their experiences and personal testimonies that people were sharing even on these public forums means that people are not wholly deterred from speaking openly by the less private nature of the space.

It is important to acknowledge also that in focusing on online spaces, we have not been able to represent the voices of those who are unable to access these spaces - for instance, through digital exclusion rendering online services inaccessible. Part of our policy recommendation process involved considering particularly how the benefits of online spaces could be realised by digitally excluded communities.

Experts and practitioners we spoke to also raised how people may also be systematically excluded from accessing certain services by other barriers, such as language: and that particularly those communities most likely to face these barriers were also likely to be disproportionately affected by Covid-19 and health inequalities and potentially be in need of greater support. Given that we also only examined forums and posts in English, these are groups we were unable to represent, which is a limitation of this research we would hope further research could address. This is all the more important to understand in the wake of Covid-19, given, as one workshop practitioner noted, the “sudden spring of grassroots safe spaces online for those who felt excluded or marginalized from traditional (digital) services.”¹⁷ Importantly, some of this will have built on existing offline communities and networks, or saw an online group widening its remit, offering people vital familiarity and more tailored support. As New_Public’s report, *Terra Incognita*, into how social infrastructure digitised in New York City during the pandemic notes, access alone is not the end of the story when it comes to support, since “those who did make it online [still] had to navigate new cultures, etiquettes, and improprieties”.¹⁸

¹⁷ Rini Jones, in our workshops

¹⁸ Sloane, M. and Kraemer, J. *Terra-Incognita NYC: Mapping New York City’s New Digital Public Spaces During the COVID-19 Outbreak*. New Public. 2020. Available at: <https://newpublic.org/uploads/2021/03/Terra-Incognita.pdf> [date accessed: 07/05/21]

Though our policy focus is the UK, there were also posts within our dataset from wider geographic regions, and thus we hope that our findings may also reflect people's experiences in other countries, but we were unable to control for geographic origin of a post.

Though we examined discussion of religious themes around life and death, the diversity of religions discussed in our dataset was low: with only 132 statements out of the total dataset referencing faiths other than Christianity or being non-religious. Whether this is representative of the demographics who use these forums is outside the scope of this report, but it is important to reflect that the voices of those from different faiths may be underrepresented.

When examining posts, we were only able to examine posts in isolation, rather than as part of the conversation they were initially a part of. While in some cases it was possible to infer the context, in others, the wider meaning was not clear.

Where we have included quotes from forums in this report, these have been bowdlerised. This means that we have changed the exact words used to protect the privacy of the author, while preserving the sense of the text. Where names appear in quotes, these are not the original names used.

SECTION 1: COMFORT

People turn to online spaces to discuss a wide range of things related to death and dying, from funeral arrangements to near-death experiences. But throughout this diversity, we identified three key needs that people demonstrate through their conversations online: a need for comfort, particularly from other people online; a need for capabilities, and to empower themselves through learning from online spaces; and a need for community, and to build relationships, even with strangers, through support and solidarity. By catering to these needs, online spaces are acting as a crucial cornerstone of sustainable support for people at the end of life.

People who are experiencing life-limiting illnesses, accompanying someone at the end of their life, or who have been bereaved, can be in need of comfort, in the face of uncertainty, pain or fear. But this can be hard to come by in our everyday offline lives. Sometimes, experts we spoke with told us, it can be easier to seek comfort from strangers: people who are separate from the situation can be better placed to help in sensitive situations, while the solidarity and recognition of those who are in a similar situation to our own can be a valuable source of comfort.

It is important to recognise that 'comfort' in online spaces may not look the same as what we describe as 'comfort' usually - and that in fact, this is part of their value: that when people aren't receiving the kind of comfort they most need in their offline life, they turn to online spaces. And these spaces are also places where people can discuss and exchange as well as seek comfort - about what they find gives them comfort, and what may comfort others in their times of need: from animal companions to thinking about what may come after death.

COMFORT WHEN IT CAN'T BE FOUND ELSEWHERE

Within discussions that centred around grief, many people were speaking about the online forums as places to turn when they had nowhere else - either because they were alone, lonely, without support systems nearby, or didn't have spaces elsewhere where they were comfortable sharing their grief.¹⁹ In addition to providing this, many found these spaces to be useful repositories of wisdom around the processes and lived experience of grief and its various forms, which helped them not only feel less isolated but also better understand their own experiences of grief.

We trained a classifier in combination with a keyword filter to specifically pick out posts expressing these sentiments, to look more closely at how people were talking about their experiences when online spaces were the only place they could. The filter focused on picking out references to the online space (e.g. 'this website' 'this place'). It also picked out references to loneliness and cognate phrases (e.g. 'nowhere else to turn').²⁰

We saw that people who are grieving wanted the understanding that only others experiencing the same could offer - a place to share real feelings, in the knowledge that others would be able to relate and listen without resorting to the standard offer of condolences. The forum is often seen as a safe place that people can turn to for support and understanding - which may not exist elsewhere. The top three phrases which were most unique to this dataset included 'fog' (5 uses) 'a lifesaver' (5 uses) and 'among kindred' (4 uses): which taken together speak to the crucial role of being able to connect with other like-minded people through the online forum while dealing with the experience of grieving - not to solve, but to recognise their pain.

¹⁹ Participants in our workshops also made these observations based on their experiences

²⁰ This identified 733 posts, 437 of which were unique, within the broader dataset of 55,275 posts which were classified using the first classifier relevant to Grief.

This reflects what we were told by experts we consulted, who highlighted that often, when faced with difficulties around illness or death, people are looking for support and understanding from other people who are or have been in the same situation as they have. People want the freedom to express their experiences outside of prescribed settings or in social situations, and want their experience acknowledged - not necessarily seeking advice, but seeking reassurance that their experience is valid.

People who are grieving just need to be heard, whatever it is. They do not need advice, platitudes and suggestions...that's why I treasure this place. There aren't any wrongs or rights. There is grief, and helping each other just with understanding as only someone else who is grieving can do. [bowdlerised]

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. [bowdlerised]

Throughout a series of clusters of common words co-occurring in this dataset, we saw discussion of time - from days, weeks, months to years - suggesting that people are using online forums as spaces where they can express grief days, weeks, months or years after other people have moved on, or when it is seen as no longer 'socially acceptable' to be grieving. Many clusters highlighted that people were expressing feelings of grief and loss long after the event of a death itself.

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. [bowdlerised]

We also found that these spaces are places where people can share difficult emotions that they might feel they can't share elsewhere. In the dataset of posts related to discussion of animals that we examined, we found a significant concern comes from owners who had their pets euthanized and are uncertain about whether it was the right decision: demonstrating the value of these spaces as trusted communities, as other users who have experienced similar conflicts are able to offer reassurance and comfort to others.

We question it completely, tear ourselves apart over it. It is such a hard decision to make - perhaps the hardest - I know. However we wouldn't decide to if we didnt also have lot of concern and love for them. [bowdlerised]

A recurrent theme was also that people don't appreciate the bond that some have with their

FIGURE 6
TOP USES OF KEYWORDS RELATING TO BEING LONELY AMONGST THE WHOLE DATASET

keyword.match/keyword-count-matches	Totals
[lonely]	570
[loneliness]	357
[have no one]	52

FIGURE 7
AN EXAMPLE OF A CLUSTER WITH KEYWORDS RELATING TO GRIEF LASTING FOR A LONG TIME AFTER THE EVENT OF A DEATH

Term	P
time	0.031
years	0.020
i've	0.020
forward	0.019
ago	0.017
coming	0.017
husband	0.015
months	0.015
lost	0.015
move	0.014
friends	0.014
life	0.014
felt	0.012
grief	0.012
spend	0.010

animals, including those for whom their pets were their main or only companions. In a cluster analysis of our animals dataset, mentions of 'family' and 'home' ranked high, and a surprising word analysis showed the same for 'soulmate'. Close reading brought out how some had already lost the people in their lives, felt abandoned by them, or found connecting with people difficult. All this made their relationships with their pets vital to them (for this reason the newly grieved sometimes expressed an interest in getting a pet). However, it was clear that people felt that others outside the forum did not understand what they were going through, and struggled to relate: the forum provided an important source of comfort they couldn't find elsewhere.

I am sorry you've encountered others that don't understand. The loss of a dog is enormous for those of us who love them as much as we do. [bowdlerised]

For a long time I cried and cried - more than I had for some humans that I'd lost. Some people do not understand how traumatic the loss of a pet is, and I think that is the hard part. My animals are my "kids" - I don't have children - and the bond that I have with them is so strong. [bowdlerised]

SHARING SOURCES OF COMFORT

As well as using these spaces to participate in comforting others or receiving comfort, people come to online spaces to share their own experiences of comfort - sometimes as advice to others, sometimes just as a place to be heard.

Based on our initial cluster analysis, we identified that discussion of animals was a significant presence in the data. Exploring data discussing animals further, we found that this very often related to comfort, and people's need for comfort in response to death or dying. For example, in a search of the animals data for explicit mentions of some of the key overarching themes in this report, comfort, capability, connection and community, we found references to comfort coming out on top.

FIGURE 8
TOP USES OF KEYWORDS RELATING TO COMFORT IN THE 'ANIMALS' DATASET

keyword.match/Report-Themes-matches	Totals
[Comfort]	73
[Comfortable]	11
[Connection]	10

Closer analysis of posts - both those that explicitly mentioned comfort and those which did not - revealed how many derived comfort from their pets as companions after the death of a loved one, both immediately after and in the months and years following. For many, animals have a special significance as they have a connection to the deceased, especially when the person they have lost had loved or cared for the pet.

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. [bowdlerised]

We also found people sharing sources of comfort when thinking about death and dying that related not to everyday realities like pets, but to whatever they believed did - or did not - exist after we die.

We examined 'existential' posts from philosophical musings on the nature of consciousness to people describing their experiences of visiting spirits to hopes and fears about an afterlife or the lack thereof.²¹ These can be questions it is harder to find space to discuss in offline life - for instance, healthcare professionals are not trained to discuss these questions, and dwelling on questions about death can be seen as taboo - morbid, or deeply personal.

Many of these involved seeking, describing, or offering comfort. People spoke of how they found comfort in their beliefs about what happened after death - whether that was belief in an afterlife or a belief that there is no afterlife. People also spoke of the comfort they experienced through sensing that those who had passed on were still with them in some way. And others turned to these spaces, not due to their personal experience with death, but their fear of death, and their need to connect with others who could listen to and respond to their fears.

Thanks for sharing that: it really gives me some hope, to think that there is another place than this one, where we go after we die and, hopefully, meet those we love in that spirit world. [bowdlerised]

I am afraid of death. But I am more afraid of what happens after we are dead...Not knowing what happens after we die makes me clingy and anxious...How can I make these thoughts go away? [bowdlerised]

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. [bowdlerised]

21 We classified posts as relating to these 'existential' questions, with 1,392 results, of which 1,128 were unique posts.

COMFORT AT THE LIMIT

Within our subset of data concerning care, comfort came through as a theme in two ways. Firstly, as carers looking after loved ones, many users were frustrated at being unable to provide the comfort they wished they could to those they cared for due to the constraints and challenges of their circumstances and of the care system. On occasion, this view came also from those with experience of working as a care professional. As a former palliative nurse argued:

Who is better placed to hold vigil at the bedside of a loved one and comfort them then 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. [bowdlerised]

Secondly, these online spaces themselves served as a source of comfort to users. Receiving useful advice and support, sharing one's experiences, and hearing others are going through the same thing, were all ways in which people reported on these online environments being of comfort to them as carers. Moreover, given how much unpaid carers and those with loved ones in care took to these spaces to vent their frustrations, even where users were not lacking in knowledge or support, at the very least the opportunity to air their concerns was seen by users as positive.

In the context of Covid-19, people seem to be turning to these online spaces even more as places purely for support and potential comfort, in the knowledge that the situation is new for everyone and so advice is harder to come by. Users acknowledged the immense, potentially intractable difficulties some found themselves in, such as the harm social distancing would be causing to care home relatives with dementia, or people struggling to get tests given demand. In this respect, the value of these communities as sources of comfort rather than advice comes through. At the same time, this situation underlines the limits to capability in these people's lives the pandemic has engendered, pointing to the offline assistance people are not able to receive.

CONCLUSIONS

Online spaces play a unique role in offering comfort to those in need of it: not only do they act as spaces where people can freely share their experiences of what brings them comfort, but they are active sites of comfort: where simply the act of listening and validating someone's feelings can act towards comfort and healing. For those working to comfort people at the end of life, these online spaces demonstrate the power of shared experience in companionship: that as well as formal carers and companions, people find value in these informal networks of strangers.

SECTION 2:

CAPABILITY

A crucial role that online spaces play is allowing people to build their own capabilities and empower each other. Information-seeking is a part of this that online spaces are particularly well suited to - after a diagnosis of life-limiting illness, for instance, people may feel lost or uncertain about how to manage things, from sorting out legal documents to how to buy travel insurance to how to manage symptoms: relatives and carers may want to understand more about what is usual for those they are supporting to be experiencing. Conversations with experts also highlighted to us that online spaces allow them to connect with others who have experiences they can share, and help empower them where conventional support systems may not do so.

SPACES AS AN IRREPLACEABLE RESOURCE

This theme was notable in the data which related to how users were positively engaging within online forums. We found users reflecting on how these spaces' live and archived posts are a resource for them, be it for medical knowledge and experience, advice on providing care, or on how to deal with a myriad of different 'first' experiences in their processes of loss, which they feel are not or cannot be found elsewhere. These 'resource' posts are known to the more longstanding users, who will often direct new users to these or to other knowledgeable users.

Others speak to the therapeutic benefits, both in threads and in offers of private messaging, of space to vent or journal, to explain one's stories in their own terms, be listened to, at no cost, at their own pace, and at all hours of the day. On the other hand, we also saw where these spaces are pulled away from users - perhaps through a now inaccessible thread - people can feel worried at the

loss of a source of support. Some had not previously considered the unique benefits of these online spaces, and did not expect they would find them so beneficial, including those who would prefer not to have to receive condolences in person. Others had lurked in or had known of these spaces but had not felt the need to post in them, on some occasions for years. In all these positives, moreover, some users make reference to how these spaces are in these respects not only a rarity offline but elsewhere online too.

FREE TO SPEAK AND EXPLORE NEW IDEAS

Online spaces provide a valuable place where people can write and speak freely - even if they do not want or need a response, having a public place to 'journal' one's experiences can be valuable.²² And they also provide space for people to explore new ideas.

Within the 'existential' discussion, there was a great deal of conversation around scientific theories as well as personal experiences. The most surprising phrases were: (those which scored greater than 1 compared to a background sample of posts classified as not relevant to 'existential' questions)

NDE ²³
Scientific
Atoms
Beings
NDEs

The most common surprising phrases - those with more than 100 uses - were as in Fig 9.

²² Participants in our workshops also made these observations based on their experiences

²³ An 'NDE' refers to a 'near-death experience'

This shows that people are interested in engaging in conversations about a wide variety of understandings and experiences of death - far beyond the standard healthcare discussion about end of life. Near death experiences and what they mean for people's understanding of consciousness and death; whether there is a heaven; how consciousness and the mind relate to the body and to existence, and what this means for how we even understand 'death': these are questions that people are exploring in online spaces.

However, not all these interactions are positive: particularly when people are engaging in different kinds of discourse within one space, and so have clashing expectations of what is useful or helpful to say. People can offer words that they view as comforting which are not appropriate to what their listener needs - and of course, people can be critical or judgemental of other people's views on facts about life and death. Discussion which is about one's personal experience can easily segue into discussion about one's personal beliefs, indicating a need for more delineation between spaces in which more debate is encouraged and those in which, as in Section 1, it may not be conducive to the comfort that users are coming to the space to receive.

How the hell does someone think this is even slightly comforting? [bowdlerised]

You can believe whatever you want - I am not here to force you...the knowledge you know to be 'fact' means nothing after you die [bowdlerised]

EMPOWERMENT AND ITS EROSION

These spaces are also where people can speak about their feelings of disempowerment - gain advice from the community where it can help, or gain support and understanding from others who also feel that they lack agency - particularly relating to end of life care.

Within the discussion of people's experiences of caring and being cared for, feelings of disempowerment, and of carers not being listened to came out prominently. We identified a set of 1,269 statements relevant to this theme, and initial cluster analysis suggested people were engaging in a range of behaviours, including asking or offering advice related to care, voicing complaints related to care, and discussing the policy and politics of care.

For many, those engaging in care are struggling with a system that is not empowering them but against which they have to fight.

FIGURE 9
THE MOST COMMON 'SURPRISING PHRASES' - THOSE WITH MORE THAN 100 USES, SIZED BY FREQUENCY



FIGURE 10
AN EXAMPLE OF A CLUSTER WITH KEYWORDS RELATING TO EXPERIENCES OF CARE

Term	P
carers	0.031
care	0.020
services	0.020
social	0.019
carer	0.017
support	0.017
allowance	0.015
local	0.015
unpaid	0.015
centre	0.014
people	0.014
time	0.014
caring	0.012
advocacy	0.012
government	0.010

Term	Definition
tap	Used in reference to washing hands and to urostomy bags
advocacy	Used primarily in reference to social care advocates
sleepovers	Used in reference to carer shifts that require them to stay overnight
armed	Used in reference to e.g. carers being knowledgeable about healthcare/care system/law when dealing with authorities (and vice versa).
esegbona	Used in reference to the death of Christina Esegbona in 2011, after which an NHS hospital was fined for false imprisonment when it would not let her go home, and led to scrutiny of hospital control over decisions not to discharge patients for homecare ²⁴
jobcentre	Used in reference to carers' experience with Jobcentres, in quoting news stories, and a user discussing having worked in a Jobcentre
crash	Used in a reference to falls and to the care system being a 'car collision in slow-mo' [bowdlerised]
appallingly	Used in reference to treatment of family members by care staff, to support through Carers Allowance, to a government representative for carers, to employers, and to experience of healthcare by a chronically ill individual

Against a background of the wider dataset deemed irrelevant to care, the topmost surprising words were as below: suggesting that carers' daily work mixes with feelings of going into 'battle' against systemic failings. Qualitative analysis of a random sample from the dataset reaffirmed this, finding people voicing personal and political complaints with the care system, and how it was undermining their capabilities to be a carer or cared for.

When it came to complaints, the sense of capability being eroded came through. People were exhausted over not being listened to, finding local authorities, health and care services were slow to communicate, or had experiences of they or their careers being treated poorly by these. Likewise, people voiced frustrations with family members not helping with care of elderly parents. Others voiced frustrations with bodies that were set up to represent carers, feeling for example that consultations were impractical alongside caring demands, or that they wouldn't address certain topics such as money; for this reason posts from these bodies to these spaces suggests a possible solution to improving these relationships.

Touching on broader policy discussions, other targets of people's frustrations included public bodies such as the Department for Work and Pensions and the Care Quality Commission.²⁵ At a political level, particularly amongst unpaid carers, people felt they were not being listened to either, just as they felt ignored in their day-to-day dealings with doctors and care agencies, for example. Alongside these

personalised frustrations, there was awareness of broader issues that determined this, such as the impact of cuts to various public services, and some drew attention to the good motivations of many care professionals who find themselves constrained by the system.

The NHS lets us down, the social care system lets us down, social workers, DWP civil servants, and charities who say they represent us all let us down. Most councils have ignored the Care Act, which is toothless anyway. 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. [bowdlerised]

In June the Carers' Strategy is being published. Even if it is a Mercedes Benz of a carer strategy, if there's no strategy to raise awareness accompanying it, those who need to know won't know it exists, so I doubt the value of it in improving carers lives. I challenge the government to prove me wrong that it won't just be yet another strategy sitting on the shelf. [bowdlerised]

Despite these complaints, in seeking advice from those with firsthand experience, people acknowledged how these spaces helped them understand their way around the care system and potentially be treated better by it. These spaces, although they cannot fix systemic issues elsewhere in healthcare provision, do have a dual role that

²⁴ 39 Essex Chambers. Esegbona v King's College NHS Trust. 2019. Available at: https://www.39essex.com/cop_cases/esegbona-v-kings-college-nhs-trust/ [date accessed: 07/05/21]

²⁵ 'DWP' was the 8th most surprising phrase within the foreground dataset compared to how often the phrases occur in a background dataset - in this case Wikipedia (our standard comparator).

can help people claim back some of their agency: through offering support and validation, as well as practical or political advice and information. For instance, we found people seeking and offering understanding of medical procedures, the care system, and life as a carer to those who were newer to the role; we also saw that on a few occasions users suggested online campaigns, such as sharing their stories to a news show's online message board, or emailing MPs, as a way to try to combat these problems.

This support from online spaces seemed particularly useful for those for whom rapid changes in their lives had meant they suddenly had to become familiar with the technicalities of the care system, their rights as carers, and how to be 'armed' for it. There were occasional users who stated they had been carers for years yet were unaware of the support available to them until now, suggesting these online spaces ought to be more widely shared as a resource. Indeed, the value of digital access and literacy more generally in helping those in care was something users drew attention to.

The elderly and disabled need help to use computers to find services. I grew up with them, but these elderly people have never in their lives used a computer. So how can they be expected to order shopping off the internet? The web seems to be the key to getting help. [bowdlerised]

CAPABILITIES IN A TIME OF CRISIS

When it came to Covid-19, however, the limits of what online spaces could provide in terms of improving capability was brought painfully to the fore. We found 157 statements related to the pandemic within our subset of care data that focused on the idea of not being listened to. In qualitative analysis of these, people sought clarity over the rapidly changing nature of care of their loved ones who they could not visit, and advice over how to deal with care commitments given social distancing, financial difficulties, and particular challenges such as communicating remotely with deaf relatives. Users were also deeply uncertain about the best thing to do when it came to 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. [bowdlerised]

Unsurprisingly, therefore, complaints focused on people's poor experiences with authorities during Covid-19, and people insisted to others that they feel able to complain despite the strains of the pandemic on services. Complaints ranged from a lack of or delayed communication (including as a result of the NHS contacting them by post and because GPs had insufficient online booking facilities) and being kept out of meetings that in normal times they felt they would be part of, to claims from healthcare professionals that they cannot do certain things at present, and non-Covid patients feeling relegated. Perhaps most pessimistically, some complained of the difficulties in making complaints given Covid-19.

Often complaints turned to societal issues, with people drawing on their own experiences to argue that unpaid carers were being ignored in Government Covid-19 support efforts, though users spoke approvingly of Scotland's response here. Others feared care support would worsen post-pandemic as, or were angered further at perceived flaws in existing care policy being exacerbated by the pandemic, such as Personal Independence Payments and the Care Act.

CONCLUSIONS

Online spaces provide an important platform for people to be able to share information and advice - places where people can help to rebuild each other's sense of empowerment, and even to collectively organise and advocate for reform. However, this is an area where the power of online spaces may be best understood as providing crucial information about what people are struggling with - where systems are failing - and providing an arena for these experiences to be raised and heard when formal systems of complaint are not working. This power will only be realised, however, if those in power are able to listen and respond to the concerns of these communities.

SECTION 3:

COMMUNITY

Online spaces are more than just places where people speak to the 'void' and then leave - as much as offline spaces, they are places of community, where people can come together, interact, and build relationships based on mutual trust and shared experiences. Some people may find it difficult to engage with in-person or specifically designated emotional support groups: they may prefer to gather in groups where they can discuss their feelings but without the pressure of having to have these conversations. Online, people are free to congregate around the issues they want to discuss, and are free to come and go as they please: but many stay, and invest in the communities they are part of.

INVESTING IN THEIR COMMUNITIES

The discussion we investigated concerning animals in particular demonstrated how online spaces are not simply places where individual comments are posted and forgotten, but places where conversations happen over time, and where communities are built. That this came through strongly in the dataset related to animals may be that there is a particular validation found in online spaces: as is highlighted elsewhere in this report, some grieving in these spaces take comfort from strangers who nevertheless understand and recognise the difficulty of grief more than those in their offline lives, something that applies to animal loss too.

Analysis revealed a willingness to share personal details in a way that suggests mutual trust.²⁶ Cluster and surprising word analyses saw pets names in frequent usage, and names being repeated across different posts indicated that conversation about particular pets was continuing across the space.

Users are also not only using these spaces to talk about death exclusively - it might be the impetus for them engaging initially, but we found, for instance, users engaging in more 'casual' conversation, such as sharing photos of pets, which both pet owners and other users enjoyed and interacted over. Users encouraged others to share if they felt comfortable, suggesting some (perhaps moderators or longer-term users) recognised its value, both for grieving but also as a means of feeling part of a community. This quote nods to the idea that a new member of the community is likely to stay for a while, and her relationship to the community is expected to evolve and change.

Welcome, Sarah, I am so sorry for your loss. Maybe you will consider sharing a photo of your dog, or telling us a little about him, when you are up to it. [bowdlerised]

By exposing their vulnerability and having this received warmly, users appear to feel they can trust these communities. This is borne out too in the way some are on a first name basis and speak on familiar terms: they are returning repeatedly to these communities and so feel invested in them.

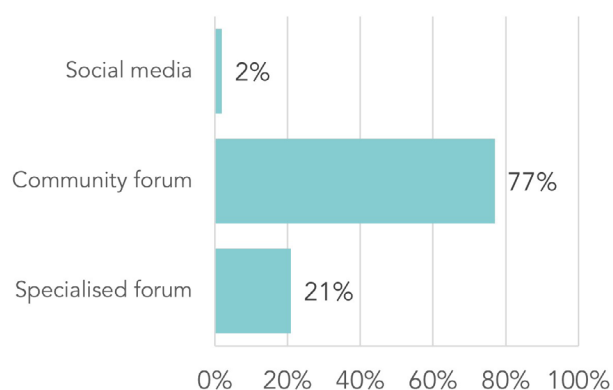
DIFFERENT COMMUNITIES IN DIFFERENT PLACES

How places are set up and run affects the kind of conversation that is encouraged; and how people use the spaces shapes their future use.²⁷ We see evidence for this, as different forums provide different communities for people to engage with. Looking at the 'existential' posts - those which were frequently much more focused on theory over personal experience - these were much more

²⁶ The causes of this are likely various - participants in our workshops suggested the disinhibiting effect of relative anonymity in these spaces, or a possible selection bias as people who were concerned about their privacy might not frequent these spaces

²⁷ Krasodowski-Jones, A. Judson, E. Smith, J. A Picture of Health: Measuring the comparative health of online spaces. Demos. 2021. Available at: <https://demos.co.uk/project/a-picture-of-health-measuring-the-comparative-health-of-online-spaces/> [date accessed: 07/05/21]; This was also raised by participants in our workshops.

FIGURE 11
DISTRIBUTION OF POSTS RELATING TO
EXISTENTIAL ISSUES ACROSS FORUMS BY TYPE

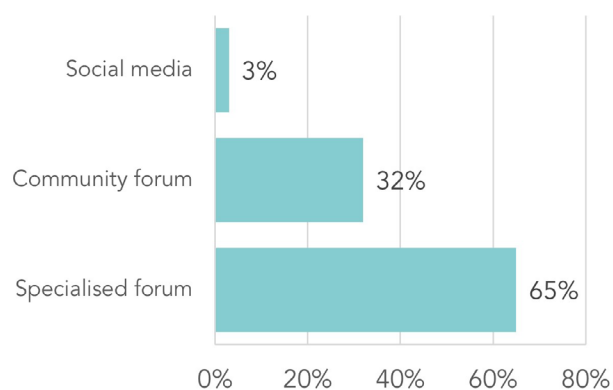


commonly found on the social media forums, even though overall, the most common type of post collected was from specialised forums. Social media forums are generally more 'political', and more explicitly encouraging of theoretical or academic discussions, than, for instance, a forum explicitly devoted to supporting people who have been bereaved is, and so the kind of discussion appropriate in one space may not occur in another space, even though the overall topic ('conversations about death') appears superficially similar.

In contrast to the existential discussions, for example, posts discussing care were largely found in specialist forums, again reflecting how superficial overlaps don't necessarily translate to broader discussion. At the same time, posts extended far beyond just care for those at the end of life, meaning it would arise in more particular ways outside of specialist care spaces. On social media care discussion was again more political, whereas on non-specialist community forums it would arise in relation to a more specific cohort that reflected the user base; for example, adult children discussing caring for their elderly relatives, rather than carers of all ages. Of course, the user base of specialist forums may also reflect certain demographics, and it is an open question as to why this might be even if they are open to all.

This points to the role of design and moderation in engendering communities of different kinds. In discussions of grief, for example, users reflected on what it meant to be presented with sub-forums catering to different kinds of loss. Some spoke about how they felt they benefited from reading about forms of grief different to their own, whereas others chose to avoid reading about additional forms because of fears of further losses in their lives. This highlights the value of a well-curated online space for discussing themes around death and dying: it can cater to all.

FIGURE 12
DISTRIBUTION OF POSTS RELATING TO CARE
ACROSS FORUMS BY TYPE



We've many losses during our lives, as others have written here, & we move through these at different times. In the four years I've been coming to this site I've never felt I must only post in one part. Our conversations, they go in many directions. I would long be gone from this site if I felt that I should only be in one place here because my grief is older. [bowdlerised]

COMMUNITY CONSTRAINED

Community was a feature of online discussions of care, but in a way that perhaps reflected the circumstances of its users. In contrast, for example, to users grieving pets, there were no mentions of names in the surprising word analyses of our care subset of data, and statements didn't generally suggest a deep familiarity amongst users. This may be due to users being carers and as such having less time available to be in these spaces. As one user noted:

Yesterday I logged on to start a discussion about social workers being controlling - particularly in hospitals - but I ended up reading up on posts from the past few months. [bowdlerised]

People were apologetic for not replying to comments addressing them sooner, an indication that they find these spaces valuable and value the community they offer, but simply lack the time to engage more. Nonetheless, there were instances of updating one another on their situations, and some users were clear that they valued these spaces deeply, feeling they have no one else to talk to about their concerns except for their fellow carers online. Moreover, many users sought advice, and more experienced carers would offer support and encourage people to message them privately if they needed someone to speak to, suggesting that

whatever their limitations, people tried to gain from and contribute as much as they could to spaces as possible.

Users, of course, do not always feel part of a community in these spaces and could on occasion be critical of their design, of other users, of site administrators, or of moderators. In a filter of our data for mentions of such criticism, we found 2,226 results. However, qualitative analysis of a random sample of these found very few actual criticisms - on the contrary, most were positive or neutral statements about the spaces and other users. What criticisms did arise covered a range of complaints: hate speech, user infighting, antipathy towards moderators, frustration with quiet threads/forums, distress over content, frustration with site design, inaccessibility of archived content, spam or health misinformation.

I'm sorry that you're disappointed you didn't get a reply: we've explained in our guidelines that on this forum we can't give advice.... Unfortunately when you say 'we' haven't replied to you, in reality it's one of Lisa, Martin or myself and checking in on this forum is just a small part of our job. I know that can be a frustration, I wish it were different. [bowdlerised]

CONNECTION IN A TIME OF COVID

What it means to be connected to others, or involved in a community, has changed dramatically over the last year, as the Covid-19 pandemic has meant that moments and means of connection have been forced to move online. And those dealing with life-limiting illnesses and the end of life have been no exception. Restrictions on visiting hospitals and care homes have meant that families have had to say goodbye to their loved ones over FaceTime, and

with restrictions on gatherings, attending funerals by Zoom rather than being able to come together in person, has become the new normal for many.

Figure 13 shows the most commonly used terms from a list of keywords almost certainly related to Covid-19 (e.g. 'Covid') and those potentially related to Covid but with broader meaning (e.g. 'test'). Zoom was one of the most common terms related to Covid that we investigated, appearing 113 times in the data.

Many of these posts were making others aware of Zoom as an online substitute for in-person community gatherings: as well as a way to stay in touch with loved ones in hospitals and care homes, doctors appointments and counselling, Zoom was discussed as a way that people could attend Death Cafes, widow groups, and carers courses.

People reflected on its merits, for example, how it is in a way preferable to an in-person meeting with a dying loved one as PPE obscures faces. Conversely, largely online communication, in combination with social distancing, meant others were struggling to grieve. Some faced poor internet connectivity, ageing laptops, and lack of digital literacy, or Zoom not being offered when they sought mental health support.

I invited my family on Zoom 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. [bowdlerised]

However, the fact that people struggled with Zoom did not mean people wanted to totally discard online options: rather, the comparative strength of online forums as places of community was highlighted. Some were reticent about the real-time nature of

FIGURE 13

TABLE OF MOST COMMONLY USED COVID-19 RELATED TERMS

keyword.match/definitely-covid-matches	keyword.match/probably-covid-matches	Totals
	[Test]	809
[Covid]		506
[Lockdown]		312
[Pandemic]		255
	[Vaccine]	205
	[Mask]	144
[Covid 19, Covid, Covid-19]		134
	[Testing]	122
[Zoom]		113

Zoom calls, but preferred the asynchronicity of online forums, and others felt Zoom 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 Zoom visit with yesterday. I wish, too, I could talk to all of you in person. I don't feel whiney here. I know often it seems that way. It's safe and caring. [bowdlerised]

RETHINKING COMPANIONSHIP

We examined the dataset to see if there was discussion of specific roles that people can play as end of life companions, based on consultations with experts from the Art of Dying Well: such as soul midwives, end of life doulas, key visitors or designated persons. However, we found little discussion which referenced these more technical terms - the 24 posts which featured at least one search term - and those which did were generally discussing or advertising events or books about end of life doulas. This is of particular interest for those seeking to engage with communities about end of life companionship, as these more specialised descriptions may not cut through widely. Just one post expanded on personal experience:

The only nursing home that they will fund is just allowing one designated person to visit people at end of life. That position will surely worsen if Covid-19 gets worse again. [bowdlerised]

There was more discussion (though still limited - we identified 58 posts) which specifically discussed dying alone, as opposed to using the technical terms we had first investigated. The main theme to come through here were expressions of guilt over loved ones having died alone. Many users reassured others that they did nothing wrong, that many may 'choose' to die alone to avoid loved ones seeing them in their final moments. This exhibits how these online spaces can be repositories of knowledge, though crucially ones in which this knowledge stems clearly from experience and is offered without judgment or expectation that these feelings can be easily 'fixed'.

My dear friend, regardless of the guilt you are experiencing - and I certainly will not try to talk you out of it - it's clear you did everything you possibly could [...] I don't think there is a person among us who would judge you as not doing enough. Still, you are your own harshest critic, and I know our voices will do little to silence that voice you're hearing in your own head. [bowdlerised]

Another more minor theme to come through was people expressing fears of dying alone, expressions which, depending on how a space is curated, could offer a route to reach out to those online to provide them with in-person support.

In the absence of such support, however, these online spaces are themselves a means of companionship. This came through particularly when we examined a subset of data that focused on specific positive interactions within forums: this was a set of posts which contained keywords relating to the forums (such as the name of the forum, or commonly used terms like 'thread') as well as a term which indicated that the poster was expressing gratitude to someone or commenting on an interaction they had had (e.g. 'your message' or 'thank you for'): a set of 184 unique posts.

Within this subset, themes emerged which reflected different positive dimensions to these spaces for users. Some of these reflect the sense of community and connection they provide: users stating how they feel they've been accompanied along stages of grief or illness; users 'checking-in' on one another for updates; users thanking others (in a sense rewarding them) for their commitment to supporting one another in the space; users offering 'virtual hugs'; users being there at potentially acutely lonely times, such as Christmas or Valentine's Day. Such examples illustrate the many ways to be a companion to those experiencing issues around death and dying in addition to end of life companions, even if these are just brief, informal interactions with relative strangers. It also highlights some of the strengths of online spaces for companionship, such as the chance for interaction with another person if you are isolated or at all hours of the day, and the potential for large-scale interaction when these spaces are busy.

CONCLUSIONS

It is clear that online spaces are not, as sometimes described, an inferior substitute for a 'real-life' community: rather, these are real communities, who, often with minimal oversight from a platform or moderator, will build and invest in themselves.

For those who participate, the presence of a sustained, reliable community is much more valuable than simply the fact of being able to talk to someone else via an online platform. However, these online spaces are not perfect. Although they will not be suited to everyone, there is still much to do to make these spaces more accessible for those who want to engage but are prevented due to a variety of barriers.

THE FUTURE FOR ONLINE COMMUNITIES OF SUPPORT

What role online spaces play in supporting people through the end of life is already and rapidly evolving. Some of this change - such as the role of Zoom in facilitating end of life connection and care - has been precipitated by the pandemic, but people may still find value and continue its use in certain circumstances, now that it is a cogent possibility.²⁸ Practitioners and experts highlighted to us that offering hybrid support that includes online support is now crucial - particularly to ensure people have consistent access to different forms of support.

Other change, however, is due to the rise of new platforms and online services that use different technologies, serve different demographics and operate under a different set of norms. An example of a new, as yet unexamined space, is the #griefftok community, a hashtag used on the video-sharing app TikTok to find and share discussions of loss and bereavement.

Which communities thrive, which are invested in, made safer, more accessible, is not, however, ultimately determined by the users of those spaces:

it will be decisions made by the companies and organisations who provide the platforms, and in some instances, even governments. This highlights both risks and opportunities: risks, because although, for instance, specialised forums have real value to their members, it is the large social media companies that have the power to reach the most people. On the flip side, if people rely on certain communities for support, and then companies are no longer able to continue operating - such as when Trump threatened to stop TikTok operating in the US - it will be individual users, looking for support, who end up bearing the brunt of these geopolitical decisions.²⁹

A good web is not one where the communities you can build, or the support you can receive, is contingent upon the whim of a tech company or government. We need a robust diversity of spaces where users are empowered to shape the kind of community they want to see, to meet the specific needs they have, to enable people to provide and find comfort, capability and communities online throughout their lives, up to but crucially including, at the end of life.

28 From expert interviews with practitioners

29 Paul, K. Trump's bid to ban TikTok and WeChat: where are we now?. The Guardian. 2020.

Available at: <https://www.theguardian.com/technology/2020/sep/29/trump-tiktok-wechat-china-us-explainer> [date accessed: 07/05/21]

CONCLUSION

Online spaces can be an essential part of democratising care and support at the end of life: they can help provide unique forms of support, can help empower people, and identify where existing systems may not be succeeding.

What we see is a clear need for people at the end of life to be supported to have agency in the process, to understand and be able to freely discuss the challenges they face, and be centered in determining the support they require. Part of this must be that people are able to have high-quality, meaningful communication with all the support systems and services they encounter. It is also crucial, however, to recognise the value of, and develop the possibilities for, informal advice and support from peers as part of a holistic approach to end of life care.

We can see that people have clear needs that are not being adequately met - whether they are dealing with a life-limiting illness, caring for someone who does, or are coping with bereavement. The difficulty of talking freely about death, combined with social or physical isolation, often means that people are turning to online spaces out of necessity: they are not receiving the support they need elsewhere, either through formal services or through their own community and support networks.

Online spaces are providing an essential function in filling these gaps. Practitioners in our workshops highlighted how this kind of peer-to-peer support can meet many people's needs, and thus also freeing up more specialised services for those who need it. But online spaces cannot be the whole answer: though they are a crucial part of providing emotional support and practical guidance to people, they cannot alleviate the more systemic problems in end of life care: of people feeling disempowered, alienated, or afraid. Policy and practice around end of life care must go beyond meeting people's medical needs, and centre also their emotional,

psychological, and social needs. There is also a need to demystify conversations about death: to build greater public understanding around people's experiences and needs at the end of life, so that people are better equipped to react supportively to others who are in need. This is needed not only to enable people to better support friends and family, but to enable practitioners and health professionals to more easily engage with people about death, dying and advance planning that will help people have better experiences at the end of life.³⁰

We have seen that online spaces contribute positively in their own right to people's experiences around the end of life: that they provide sustained sources of community, facilitating connections between people who may be miles apart, but whose shared experiences can be a source of validation, comfort, and empowerment. They need investing in, and protecting for the future.

A WAY FORWARD

Support around the end of life, for carers, patients, and their loved ones, should be centred around what an individual needs and chooses. The recognition that online spaces can provide unique forms of support and unique insights into people's experiences highlights the need to increase the diversity of options available to people and, crucially, highlights that options must not only be available but accessible and effective, to best meet the needs of people at the end of life.

However, across our research, listening to voices from users of these online spaces to end of life care practitioners and policy experts, a tension between support diversification and coherence has arisen time and again. On the one hand, the value of online forums and peer-to-peer support, combined with the potential risks of online forums run without oversight, means that there would be likely benefits

30 With thanks to participants at our policy and practice workshops

to formalising the role of these forums in health service provision, with greater oversight, presence of and support for individuals in online forums from health professionals and practitioners. However, part of the unique value of these spaces for many people is exactly that they are informal spaces, where communities can develop freely, and who can collectively determine how they use and run the space, without many of the barriers that people face in engaging with more 'formal' support services.

Support must be coherent, joining up different aspects of care and with different parts in dialogue with one another. But at the same time: those dealing with issues around death and dying have varying needs, and face varying barriers to engaging with health services: there must be a diversification of support in various regards; formal to informal, professional and peer-to-peer, online and off, and much else. A one-size fits all approach cannot be successful.

We believe that this tension can be resolved by approaching the balance of diversification and coherence through a new model: where the role of formal and informal support services online is clearly defined but with ongoing communication and collaboration between those involved, to share best practice and ensure that people have clear information about and access to a wide variety of forms of support.

By developing and investing in diverse forms of support, which are tailored to different groups with different needs - people with different levels of clinical need, communities at risk of exclusion or marginalisation - people would have more choice and more of a chance to meet their specific needs.

And not only choice - people would have increased agency with greater information and awareness of the available options, and support to engage with them. For instance, people would have more points of access to a whole ecosystem of support. Whether from searching for 'grief support' on Google or speaking to their GP about their mental wellbeing, shared resources and signposting would help improve equity of access.

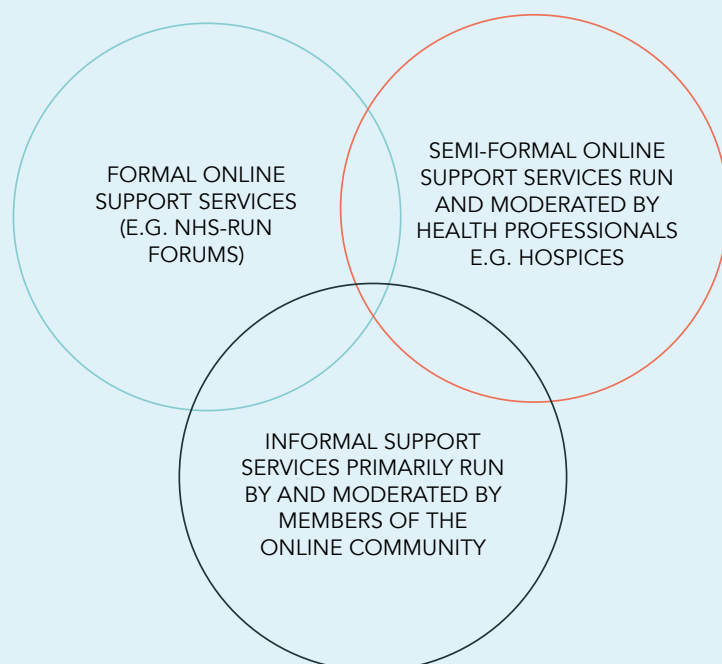
Establishing mechanisms for these services to work together - whether that is information-sharing, collaboration on online signposting or resource development, or working groups to facilitate better communication - would help the 'formal' services learn from the best practice of the informal online communities. Likewise, online communities could improve their own safeguarding and wellbeing approaches: reaping the benefits both of systematising peer-to-peer support and of supporting organic community growth online.

Below we present immediate recommendations for how existing support could be improved, and then set out a model for how different kinds of online support could form a coherent part of health service provision, whilst maintaining diversity of forms of support available.

Diverse forms of support should be invested in and developed

But these should operate coherently, not in siloes: accessing one should mean you also have an entry point to the others

People should be empowered to understand the diversity of support available and be able to choose what forms of support they access



Recommendation 1: Government (including DCMS and DHSC) should invest in addressing the digital divide, and support both users and providers to better engage with online services.

This should be achieved through:

- The creation of a Minimum Digital Living Standard: a 'universally recognised baseline for what it means to be digitally included in the UK'.³¹
- Supporting community organisations that help people at risk of digital exclusion
- Investing in digital infrastructure in less well-connected areas.
- Supporting organisations providing services to people at the end of life to upskill staff digital skills. For instance, where forum moderators are employed, these should be people with a mix of digital skills and training in end of life care, mental health and safeguarding.

Recommendation 2: Health services and practitioners should continue to develop hybrid models of end of life support post-pandemic, including online, telephone and in-person support, to facilitate greater patient choice and access to a wider diversity of forms of support.

Where new online systems have been set up through the pandemic, these should be retained but will need 'reorienting' to ensure they are continuing to meet people's needs and meet the same standards as offline services offered.^{32, 33}

Recommendation 3: Organisations which provide online forums should clearly signpost key information about the forum and what it offers to users, and what alternatives are available.

This information should include what their purpose, guidelines and policies on moderation are, how users can be supported to engage in the forum if they are at risk of exclusion and signpost users who may need support beyond what that forum can offer to other forums or resources.

Recommendation 4: In developing online forums, organisations supporting people at the end of life should ensure there are options tailored to support specific communities at greater risk of exclusion from accessing online services - for instance, people who primarily speak languages other than English.

These should be created in collaboration with the relevant communities and mechanisms should be put in place to ensure these forums continue to attend to the risk of exclusion in the future.

Recommendation 5: Health services and local authorities (e.g. through a mechanism like ICS Health and Care Partnerships³⁴) should engage with organisations who provide online forum support to identify where there are common complaints of systematic failures that could be addressed.

Moderators of these forums should also be empowered to signpost people who raise these issues within forums to official routes or provide support for raising their grievances if desired.

Recommendation 6: The role of animals and pets in end of life care and companionship should be more widely recognised.

Care homes, hospitals and hospices should facilitate visits, working together with families as well as organisations that provide pets as therapy, to better support people at the end of life.

Recommendation 7: Leading organisations providing support and care at the end of life, those providing online forums, and tech companies should work together with the NHS to create a shared database of online forums supporting people at the end of life, with details about who they are for and how to access them.

This should be publicly searchable, and signposted across the spectrum of forums: it should be available to healthcare professionals to enable them to direct patients, moderators of forums so they are able to direct users to other forms of online support if needed, and tech companies to facilitate better automated signposting of support services to users of online platforms. This should include a wide range of forums from informal to formal, and covering a diversity of types of platform aimed at different audiences. This would enable people to engage with a variety of forms of support, from whichever point they had entered the support ecosystem.

Recommendation 8: Organisations running forums should establish a mechanism through which they can share their experience and best practice in providing, running and moderating online forums.

31 Bowyer, G. Grant, A. and White D. Learning From Lockdown: 12 Steps To Eliminate Digital Exclusion. Carnegie UK Trust. 2020. Available at: <https://www.carnegieuktrust.org.uk/blog/learning-from-lockdown-12-steps-to-eliminate-digital-exclusion/> [date accessed: 07/05/21]

32 Horton, T. Hardie, T. Mahadeva, S. Warburton, W. Securing a positive health care technology legacy from COVID-19. The Health Foundation. 2021. Available at: <http://health.org.uk/publications/long-reads/securing-a-positive-health-care-technology-legacy-from-covid-19> [date accessed: 07/05/21]

33 Covid-19 Committee. Beyond Digital: Planning for a Hybrid World. House of Lords. 2021. Available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldcvid19/263/263.pdf> [date accessed: 07/05/21]

34 Department of Health and Social Care. Integration and innovation: working together to improve health and social care for all. UK Government. 2021. Available at: <https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version> [date accessed: 07/05/21]

This should include representation from a diverse range of forums, including both small community chat rooms, specialised forums managed by healthcare professionals, and large social media platforms to maximise the impact of knowledge sharing.

Recommendation 9: NICE should conduct a review of the evidence specifically of online forum support (as opposed to digital health interventions more broadly) as part of end of life support and care for patients, their families and friends, and carers.³⁵

This could include commissioning clinical trials to investigate the outcomes for people's wellbeing and mental health of engaging with different kinds of online support, for people with different needs. This would then provide a knowledge base through which care and support around the end of life could be better tailored to people's individual needs. This could form the basis, if found likely to be effective, of developing forums which are NHS-branded and staffed by mental health professionals, and contribute to the development of clearer guidelines for people seeking support as to what is most likely to help them.

Recommendation 10: NICE should develop a standards framework relating to online forums.

This could build on existing frameworks for using digital technologies and work together with leading organisations providing support and care at the end of life.³⁶ These standards could be used to certify that forums relating to end of life care and discussions meet standards of moderation, safeguarding procedures, privacy, and clarity to users identified as necessary through an evidence review (as above). This would enable signposting of forums, such as through a shared database, to be more effective and reliable.

Recommendation 11: Organisations which run community forums which are run by community volunteer moderators should incentivise, reward and support this digital civic labour

Those who engage in community moderation should have clear access to support and resources to help them in moderating and supporting others in a peer-to-peer community group, from guidance on safeguarding to emotional wellbeing support for themselves, and be rewarded for their efforts.

35 O'Donnell, H. Lugton, J. Swenson, C. Pagliari, C. Digital Health Interventions in Palliative Care: A Systematic Meta-Review and Evidence Synthesis. medRxiv. 2020. Available at: <https://www.medrxiv.org/content/10.1101/2020.09.16.20195834v1.full.pdf> [date accessed: 07/05/21]

36 National Institute for Health and Care Excellence. Evidence standards framework for digital health technologies. 2021. Available at: <https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies> [date accessed: 07/05/21]; NHS. Digital Technology Assessment Criteria (DTAC). 2021. Available at: <https://www.nhs.uk/key-tools-and-info/digital-technology-assessment-criteria-dtac/> [date accessed: 07/05/21]

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15 WHITEHALL, LONDON, SW1A 2DD

T: 020 3878 3955

HELLO@DEMOS.CO.UK

WWW.DEMOS.CO.UK