THE DEATH DESIGNER REPORT

NOVEMBER 2021

Examining the evolution of deathcare

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OVERVIEW

When we begin to think about how a system was designed, many questions arise. Who designed it and for whom was it designed? In fact, was it designed at all or did it come about organically?

These are the kinds of questions that led to this report.

Deathcare in the United States was already rapidly changing in the years leading up to the pandemic. And then COVID absolutely overwhelmed our system. More people have had to face, voluntarily or involuntarily, their own mortality and the mortality of others. We have been repeatedly shocked by images of despair—of cooling trucks brought to New York City to handle an overflow of bodies, of loved ones separated from a dying family member, of social injustices worsening—and by headlines that bring despairing news ever closer.

A positive result of increased demand and awareness for deathcare is that many new faces have entered the space, particularly in the form of deathtech startups, end of life doulas, and entrepreneurial individuals who are responding to needs within their communities. In order to better understand the evolving deathcare ecosystem, we decided to delve into details of daily practice and priorities of those who are currently working in the end-of-life and deathcare industry.

Both qualitative and quantitative data was gathered beginning with a series of workshops conducted in the summer of 2021—one of which was co-facilitated with Nix Kelley—and then by creating a survey in partnership with Eva Ting, founder of Here to Honor, that was distributed among community members in the fall of 2021.

This report is a living document, meaning that its content will continue to be revised and updated in collaboration with people like you, the reader. Throughout this report, you will find invitations to give feedback and to add information that may inform future iterations of this work.

Thank you for your interest in helping us all to better understand the evolution of deathcare.

Isabel Knight,
Founder of
The Death Designer

WORKSHOP

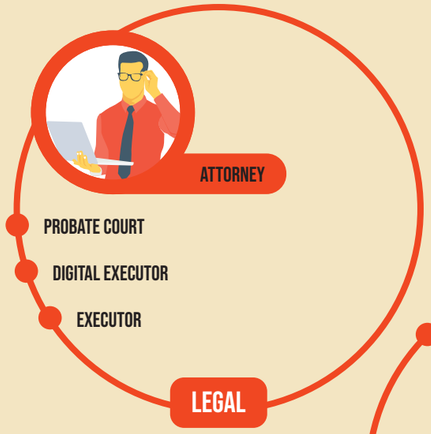
During the summer of 2021, we conducted 6 human-centered design workshops with the goal of further understanding the problems that need to be solved in different areas of the rapidly evolving deathcare space. We started out trying to understand how the pandemic had affected deathcare but the scope quickly evolved into other spaces, such as trans deathcare and the differences between medicalized deaths in a hospital setting and violent or traumatic deaths.

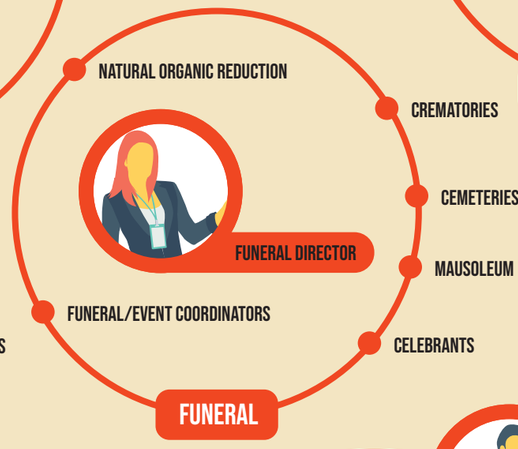
We used the collective knowledge of dozens in the deathcare community to map out the various stakeholders in the deathcare space, and we plotted the journeys of the 2 separate paths we identified as “medicalized” and “nonmedicalized” death.

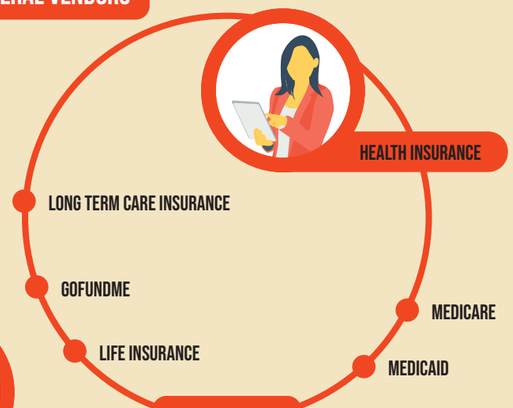
All of the maps shown here are living documents, and as a viewer of this report, you are welcome to reach out to add or suggest edits to these documents at any time. You may also view the original versions of all maps and exercises at the links in the appendix.

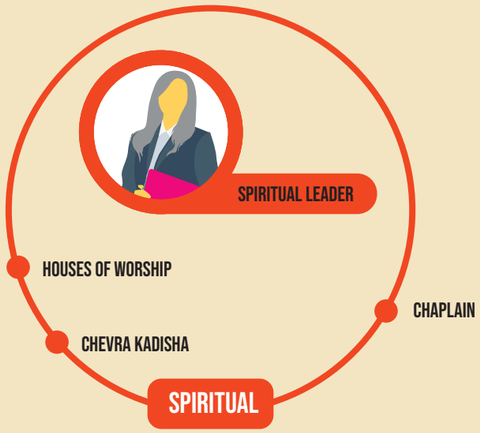
DEATHCARE STAKEHOLDER MAP

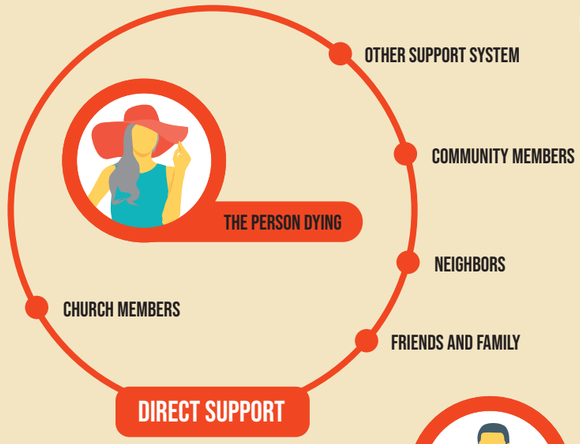
This map diagrams different actors in the deathcare system. The content here is a reflection of a collaborative process in which participants in the Death Designer workshop brainstormed all the stakeholders they could think of, and is not intended to be a comprehensive diagram. If you would like to add to it, please contact Isabel Knight at isabelxknight@gmail.com.

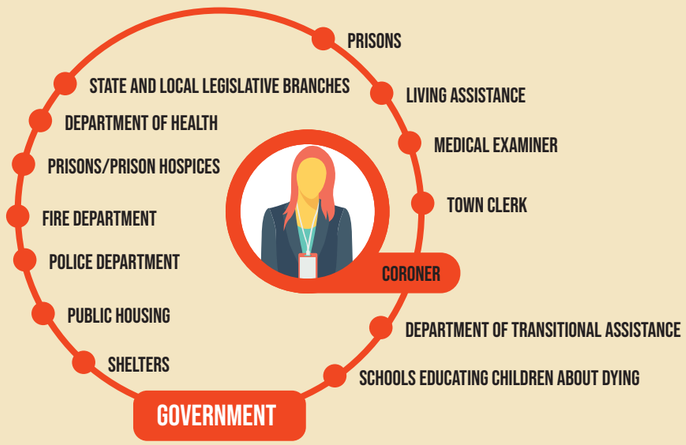


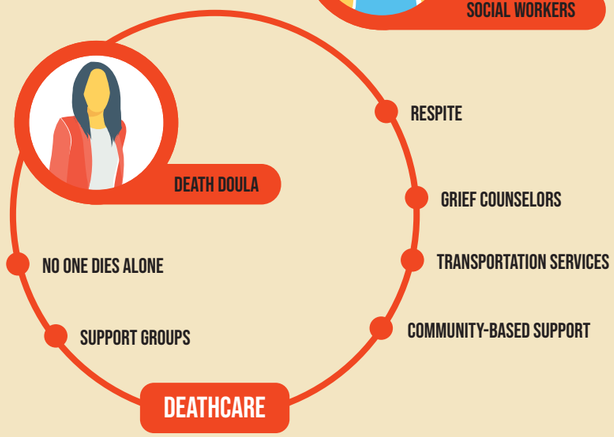


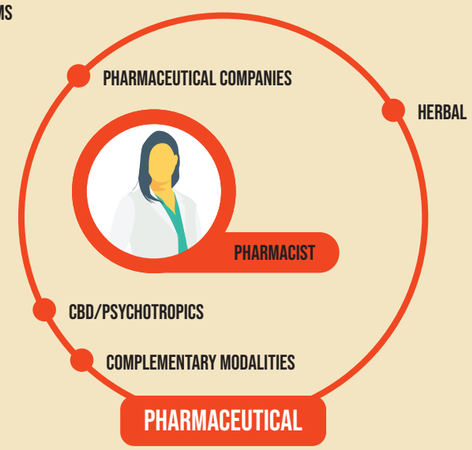






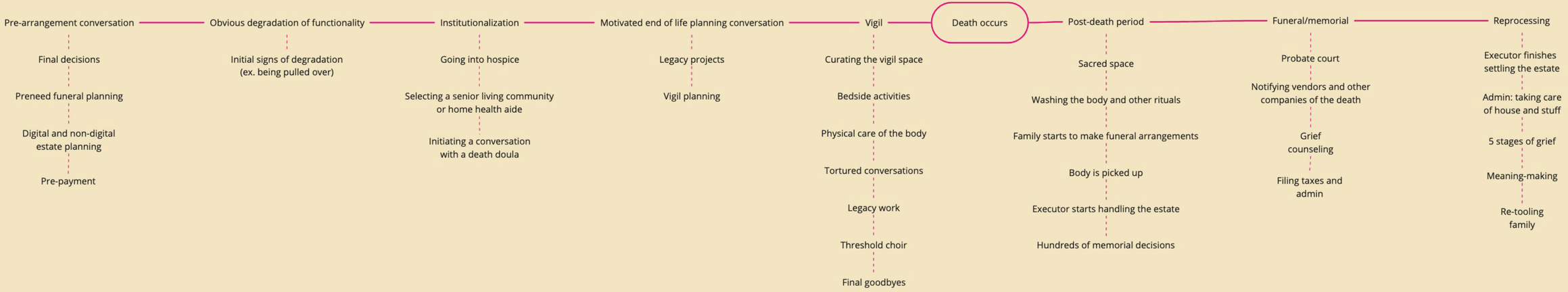






MEDICALIZED DEATH JOURNEY MAP

Here we map out the journey for a person going through the end of life process. We use the term "medicalized" death to refer to an expected death where someone dies of a medical condition in a hospital or in their home. This map is not intended to be comprehensive, but a snapshot of the details we came up with during the workshop. To add your insights to this map, please contact Isabel Knight at isabelxknight@gmail.com.



Pain Points

- Natural reticence to deal with end of life issues leaves less room for sacred space since you have to deal with so many logistics
- People of color are less likely to have advance directives

Possible Stakeholders

- Doctors, nurses, medical staff
- Attorneys
- Family or friends

Possible Opportunities

- Opportunity to educate on funeral options
- Potential to find more jumping off points to initiate these conversations

Pain Points

- Dying person afraid of giving up dignity and losing control
- Cognitive dissonance for parents of children who are dying
- General anticipatory grief among family and friends

Possible Stakeholders

- Doctors, nurses, medical staff
- Police or other emergency staff

Pain Points

- People of color have worse healthcare outcomes
- COVID: Shortages of medical supplies such as ventilators

Possible Stakeholders

- Doctors, nurses, medical staff
- Nursing homes, home health aides
- Death doulas

Pain Points

- Can be difficult to find info on end of life planning if you have not gone through the process before, who do you go to?

Possible Stakeholders

- Doctors, nurses, medical staff
- Death doulas

Possible Opportunities

- Opportunity for creative ways to foster physical connections in this stage

Pain Points

- 80% of people want to die at home but only 20% do
- Some states have laws around hospice not providing recommendations

Possible Stakeholders

- Hospice nurses, volunteers, staff
- Death doulas
- Chaplain/religious leaders

Pain Points

- Lack of transparency in funeral pricing
- Lack of a neutral 3rd party to advise about funeral options
- Lack of support for sudden death (where do you go if you don't have hospice?)

Possible Stakeholders

- Hospice, doctors
- Death doulas
- Possibly police or EMS

Pain Points

- COVID: Shortages of funeral home space

Possible Stakeholders

- Funeral directors
- Cemetery workers
- Crematory workers

Possible Opportunities

- FEMA Relief and other forms of crowd funding
- Opportunities to offer memorials that speak to different cultural traditions

Pain Points

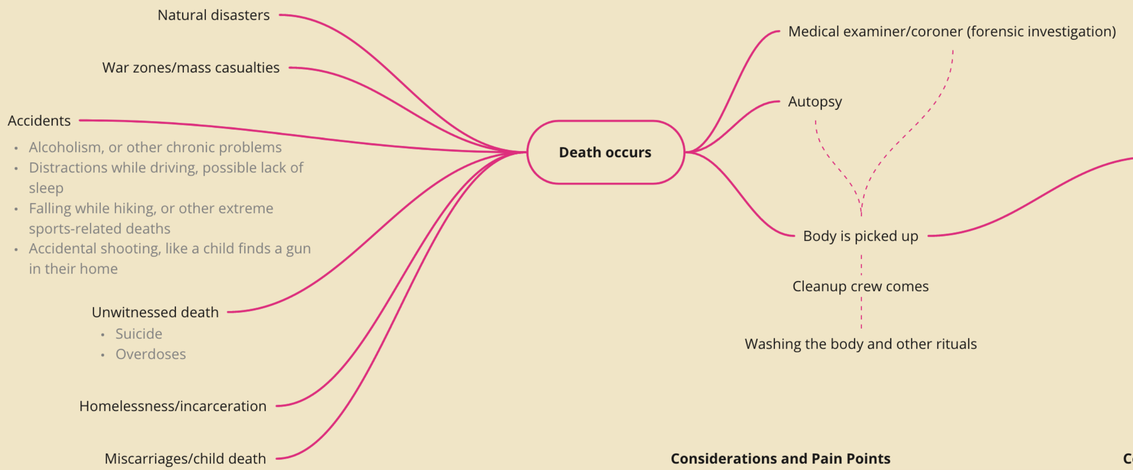
- Average is 570 hours to settle the estate
- Cognitive dissonance for parents of children who are dead

Possible Stakeholders

- Grief counselors
- Therapists
- Executor

NONMEDICALIZED DEATH JOURNEY MAP (TRAUMATIC DEATHS)

Here we map out the journey for a person going through the end of life process in a nonmedical setting. We decided this needed to be a separate map because the dying process for a violent or traumatic death looks so different from the medicalized death, which is often considered the "default" way to die. We felt this map would be useful for people who work with marginalized communities that experience a greater threat of violence. Not all of the steps included here are meant to represent the steps that occur with every death, and are by no means comprehensive, but rather a suggestion of steps that could happen since the range of nonmedical deaths varies widely. To add your insights to this map, please contact Isabel Knight at isabel@thedeathdesigner.com.



Considerations and Pain Points

- Do the people who find the body know who to call?
- People may take you to the ER and then drive away
- Homelessness: no next of kin, state needs to decide how to dispose of the body
- Miscarriages and child death:
  - In Ohio, you need to have a funeral for the baby
  - CA takes the opposite approach
  - In case of genetic condition, coping with the fear that your child will die
  - Child needing to cope with their own mortality

Possible Stakeholders

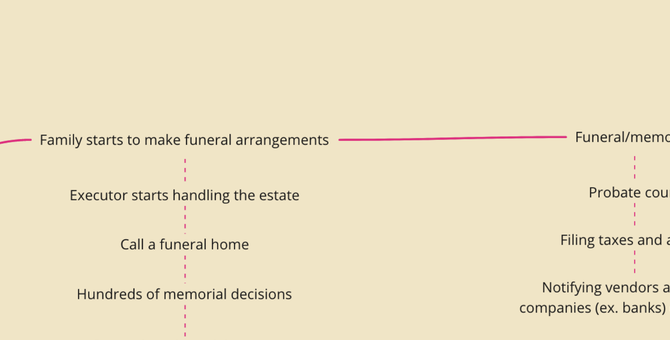
- Doctors, nurses, medical staff
- Genetic counselors
- People who find your body
- Police
- Search and Rescue
- Therapists
- Welfare service staff
- Prison guards, staff
- FEMA

Considerations and Pain Points

- People often hear of the death on the news
- Landlords, bystanders, and others living in the building also traumatized from witnessing a shooting
- Families might be grilled by detectives
- Dealing with social services, kids being taken away
- Pain Points:
  - Lack of neutral 3rd party to advise about funeral options
  - Lack of support for sudden death (where do you go if you don't have a hospice?
  - Fights over who pays for the autopsy, can be situations where some parties don't want the autopsy like if the police shot the victim
  - Autopsy findings can be fought over and a second autopsy ordered

Possible Stakeholders

- Police
- Ambulance, EMS
- Doctors
- Therapists
- Journalists, news people
- Forensic Pathologists
- Investigators
- Coroners
- People who witnessed the death



Considerations and Pain Points

- Discussion of whether to have a wake in case of body mutilation
- Indigent bodies get housed at the medical examiner's office until one of the few funeral homes that take indigent bodies will take it
- State won't pay enough to cover a cremation, so the funeral home has to eat the cost

Possible Stakeholders

- Family and friends
- Executor of wills, trustees
- Funeral director
- Body donation center staff
- FEMA (for example, if receiving FEMA funeral funding)

Opportunity Areas

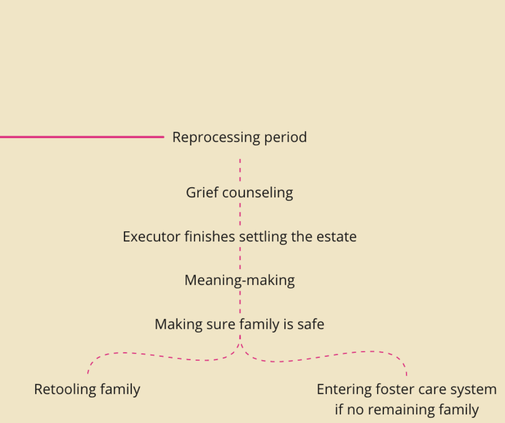
- FEMA Relief and other forms of crowd funding for funeral expenses
- Lobby state to offer more money for indigent deaths/funeral help for families

Considerations and Pain Points

- Worried about rival gangs showing up at funeral, etc.
- Cremation obliterates all evidence of what happened
- Some cultures do require a wake/viewing if possible, which can be difficult if the body is in a bad state

Possible Stakeholders

- Funeral directors
- Cemetery managers
- Crematory staff
- Medical examiner



Considerations and Pain Points

- Sudden grief can be more intense to process, can involve blame, guilt etc.
- Cognitive dissonance for parents of children who are dying/dead
- Cycle of violence where the police are involved, kids might be better armed than the police
- Secondary effect of trauma on the healthcare and social workers, trauma emanates out
- Connection with others (non-professional) who have gone through similar experiences or friends
- Who takes over the children if parents die?
- Political activism (ex. Brown Peace Institute in Boston)
  - Often female politicians run because they have kids who are shot or are victims of violence

Possible Stakeholders

- Family and friends
- Executor of wills, trustees
- Grief counselors
- Therapists
- Foster care
- Social workers
- Politicians in cases of policy advocacy
- Foundations and advocacy orgs

Opportunity Areas

- Opportunity to use the tragedy as a way to spur political momentum
- Cure Violence - an organization that treats violence like an epidemic and tries to stop the cycle of violence before retaliation occurs
- How can we ask people "what happened to you?" rather than "what's wrong with you?"

GENERAL DEATHCARE PROBLEM SOLVE

For this exercise, participants were asked to brainstorm all of the problems they could think of in the general deathcare space. Then, we clustered the resulting ideas into themes and gave each of the themes headings. Once the ideas has been themed, we chose the two problems shown here to solve, and used a method to spark ideas known as "alternative worlds" in which we thought of how we would solve the problems if we were the head of either a tech company like Facebook or Amazon, or the head of a socialist country. The rest of the problems we brainstormed are shown on the following page.

Problems

LACK OF ADVOCACY FOR THE NEEDS OF THE DYING

- COERCED DNR'S
- TENSION BETWEEN EMOTIONAL AND SYSTEMIC/PUBLIC HEALTH NEEDS
- UNSAFE DISCHARGE FROM FACILITIES

LACK OF FINANCIAL RESOURCES

- INABILITY TO PAY
- PROLONGED DEATH PROCESS DUE TO INCREASED MEDICAL TECH
- JOB/INCOME LOSS
- UNEXPECTED COST OF FUNERAL

Solutions

POLICY WORK

- GOVERNMENT-PROVIDED FUNERAL RELIEF (LIKE THE COVID FUNERAL RELIEF BUT FOREVER)
- ADVOCATING FOR NATIONAL BEREAVEMENT POLICY/CARE
- COALITION TO TRANSFORM ADVANCED CARE (C-TAC)

DEATHCARE AS EMPLOYER BENEFITS

- BEREAVEMENT BENEFITS AS PART OF EMPLOYMENT PACKAGES

EVENTS

- CLASSES OFFERED AT FESTIVALS/EVENTS
- DOULA CARE FLYERS, ETC, INCLUDED WITH PACKETS THAT ARE HANDED TO PEOPLE IN CONTACT WITH A SOCIAL WORKER
- DEATH EXPO

WORK WITH EXISTING COMMUNITY GROUPS

- COLLABORATION AND TRAINING VIA RELIGIOUS COMMUNITIES
- DOULA SERVICES HIGHLIGHTED IN COMMUNITY MENTAL HEALTH ORGANIZATIONS
- USE EXISTING COMMUNITY GROUPS (EX. RELIGIOUS GROUPS, SOCIAL WORKERS) AS EDUCATION CENTERS
- COLLABORATING AND TRAINING VIA COMMUNITY-CENTERED ORGANIZATIONS (I.E. MUTUAL AID)
- SOCIAL WORKERS, DOULAS, ETC AVAILABLE TO HELP PEOPLE FILL OUT ADVANCED CARE DIRECTIVES
- DOULAS PLUGGED INTO HOSPITAL SERVICES, LIKE ON-CALL CHAPLAINS, ETC.
- END OF LIFE PLANNING RESOURCES AVAILABLE IN MARGINALIZED COMMUNITIES

GENERAL DEATHCARE PROBLEM SOLVE

Solutions Continued

ALTERNATIVE BUSINESS MODELS

- NEED TO CHANGE THE BUSINESS MODELS OF DEATH AND GRIEF
- IS IT POSSIBLE FOR DOULA CO-OPERATIVES OR DOULA "GROUPS" (VAGUELY) APPLY FOR GRANT OPPORTUNITIES WHICH WOULD SUPPORT SLIDING SCALE SERVICES?
- ALTERNATIVE BUSINESS MODELS (CO-OPS, PUBLIC BENEFIT CORPORATIONS) AND PAY STRUCTURES (SLIDING SCALE)
- CO-OP FUNDS FOR EOL NEEDS

MISCELLANEOUS/UNCATEGORIZED

- INCLUDE END OF LIFE CONVERSATION STARTERS/RESOURCES TO LOCAL JURISDICTION'S COVID-19 HELP PAGES
- AMAZON: KNOWS YOUR SEARCH HISTORY AND MARKETS ADVANCE CARE PLANNING TO YOU
- HAVE DEATHCARE RESOURCES TRAINED IN SEO

CAFE

- CAPITAL ONE CAFE IDEA FOR A REAL-LIFE DEATH CAFE WHERE PEOPLE CAN ACCESS RESOURCES AND PLANNING HELP
- CREATE A CASUAL PUBLIC "HUB," SPACE OR CAFE IN CITY CENTERS AND METRO AREAS WITH END OF LIFE RESOURCES
- OPPORTUNITY TO PARTNER WITH LOCAL STAKEHOLDERS AND DECISION-MAKERS TO MAKE THE SPACE MORE INTERSECTIONAL
- OFFER BOOKLETS ON WHAT THE EOL PROCESS IS LIKE WITH THINGS TO IDENTIFY AND LOOK OUT FOR
- CORPORATE SPONSORSHIP

GENERAL DEATHCARE PROBLEM SOLVE

> The problems listed here are the remaining problems we brainstormed in the workshop but did not conduct a solutioning session for. We may conduct future sessions to address the problems listed here. Reach out if you are interested in co-facilitating one of these sessions.

INEQUITY AND RACIAL DISPARITY

- DIRECT CARE WORKFORCE CRISIS
- UNSAFE FUNERAL HOME SERVICES
- UNMANAGED SYMPTOMS
- LEGAL IMMUNITY, LACK OF RESPONSIBILITY FOR HARM
- MORE BLACK AND BROWN PEOPLE ARE ESSENTIAL WORKERS
- AGEISM
- ABLEISM
- BAD STAFFING RATIOS
- ALGORITHMIC RACISM
- OXYGEN METERS WERE NOT DESIGNED FOR PEOPLE OF COLOR

MISCELLANEOUS/UNCATEGORIZED

- COMMODIFICATION OF CARE
- LIMITED/NO ACCESS TO THE INTERNET/TECHNOLOGY
- LIVING ALONE, NO FAMILY HELP

LACK OF END OF LIFE EDUCATION

- FEAR OF DEATH
- LACK OF ADVANCE CARE PLANNING
- NOT KNOWING FINAL WISHES
- LACK OF EDUCATION ABOUT DEATHCARE OPTIONS, DOULAS
- TENSION BETWEEN RELIGIOUS FAITH AND ADVANCE PLANNING
- INCREASE EOL EDUCATION/SERVICES FOR THOSE EXPERIENCING HOMELESSNESS

COVID

- UNNECESSARY DEATHS
- LACK OF PPE
- PPE NOT MADE IN THE US
- COLD STORAGE SHORTAGE
- OXYGEN AND VENTILATOR SHORTAGES
- MASSIVE DEATH IN NURSING HOMES
- CAN'T HAVE MEMORIAL SERVICES
- CREMATORIES OVER CAPACITY
- SUPPLY CHAIN PROBLEMS
- MORPHINE SHORTAGE
- VOLUNTEERS CAN'T GO TO HOSPICE
- ISOLATION
- INCREASED GRIEF FROM NOT BEING ABLE TO SAY GOODBYE IN PERSON
- OVERWHELMED HOSPITALS, FUNERAL HOMES

TRANS DEATHCARE PROBLEM SOLVE

During the general deathcare problem solve, the participants felt that trans/non-binary deathcare presented enough unique challenges to warrant its own session. The solutions listed here are all centered around education, as the group felt most of the problems need to be addressed by building awareness among both the community and deathcare and medical professionals.

Problems

WISHES BEING HONORED

- DEADNAMING
- BURAL OR FUNERAL WISHES NOT BEING HONORED
- FUNERAL HOMES NOT WANTING TO DEAL WITH CLIENTS
- GENDER AFFIRMING PROSTHETICS WITHHELD BY HEALTHCARE
- GENDER AFFIRMING PROSTHETICS AND GARMENTS CAN'T ALWAYS BE CREMATED/BURIED
- LEAVING HOUSES/OTHER POSSESSIONS TO THE PEOPLE THEY WANT TO HAVE THEM
- LACK OF RESPECT FOR CARE, FUNERAL, AND LEGACY WISHES
- NOT COMMUNICATED WHAT TO PUT IN THE OBITUARY
- NURSING HOMES/FUNERAL HOMES DON'T KNOW HOW TO HANDLE NONBINARY BODIES (EX. BINDERS)
- BEING OUTED NON-CONSENSUALLY IN DEATH
- MAY NOT BE 'OUT' AMONG NON-QUEER PEOPLE

NEED FOR EDUCATION

- NO CONTACTS IN THE FUNERAL OR DEATH CARE COMMUNITY
- NEED TO LEARN ABOUT DIVERSE COMMMUNITIES - WHO THEY ARE OUT WITH, WHO THEY ARE NOT, TO PROVIDE CARE AND SUPPORT
- NOT KNOWING WHAT FUNERARY GUIDELINES OR LAWS THERE ARE IN YOUR STATE OR AREA

GENDERED PRODUCTS AND SERVICES

- DEATH PRODUCTS CAN SOMETIMES BE GENDERED
- TRADITIONAL CEMETARIES AND FUNERAL HOMES STRUGGLE WITH NON CIS PRONOUNS
- MAY NEED TO BE IN THE CLOSET TO ACCESS HEALTHCARE/DEATHCARE
- OBITUARIES ARE OFTEN FORMATTED FOR HE/HIM OR SHE/HER
- GENDERED MEDICAL SPACES
- ADVANCE DIRECTIVES ARE TYPICALLY SET UP FOR CIS FOLKS IN HETERO RELATIONSHIPS

LEGAL

- LEGAL NEXT OF KIN IS ESTRANGED AND NOW HAS AUTHORITY IN END OF LIFE CARE OR FUNERAL ARRANGEMENTS
- HOW TO HAVE CORRECT NAME ON DEATH CERTIFICATE IF THE PERSON DID NOT LEGALLY CHANGE THEIR NAME
- LEGAL NEXT OF KIN DOES NOT NOTIFY CHOSEN FAMILY/CURRENT COMMUNITY ABOUT THE DEATH
- LEGAL/DEAD NAMES BEING USED INSTEAD OF CURRENT NAMES
- COMMUNITY NOT OBSERVED BY POLICY, LAW, ETC AS "FAMILY"
- NON TRADITIONAL FAMILY STRUCTURES BEING RESPECTED / OBSERVED BY INSTITUTIONS (REGARDING POLICY, ETC)

TRANS DEATHCARE PROBLEM SOLVE

Problems Continued

TRAUMATIC DEATHS

- DEATH RATE IS HIGHER, DEATH IS MORE PRESENT
- LIVING INTO OLD AGE IS NOT THE NORM
- TRAUMA AND PAIN ASSOCIATED WITH SUDDEN DEATH
- NO RESOURCES FOR TRAUMATIC GRIEF AND LOSS FOR TRANS/NONBINARY COMMUNITY

LACK OF FINANCIAL RESOURCES

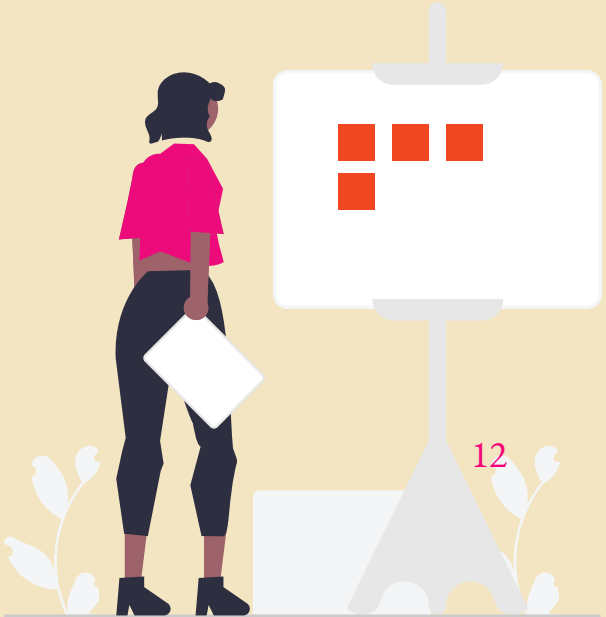
- LACK OF FUNDING
- TRANS AND NONBINARY PEOPLE DON'T HAVE AS MUCH FINANCIAL SECURITY TO PAY FOR FUNERAL SERVICES
- JOB/INCOME LOSS
- UNEXPECTED COST OF FUNERAL

EMOTIONAL TRAUMA/DISCOMFORT

- UNCOMFORTABLE FAMILY MEMBERS
- SOME FAMILIES TRY TO MAKE PEACE BEFORE THE DEATH OCCURS, SOME DO NOT
- FEELING ALONE, ESPECIALLY IF THEIR PARTNER HAS PREDECEASED THEM
- REGRETS OVER FAMILY ISSUES
- PLANNING AHEAD FOR ONE'S DEATH CAN BE MACABRE
- INDIVIDUALS BEING IGNORED FOR THEIR SEXUAL DIFFERENCES
- INDIVIDUALS NOT BEING ACCEPTED SIMPLY AS A HUMAN BEING

ACCESS TO CARE

- LACK OF TRUSTED MEDICAL CAREGIVERS
- LESS ACCESS TO COMMUNITY OF CARE IF OUTSIDE CONVENTIONAL FAMILY STRUCTURE
- ACCESS TO MEDICAL CARE AND DEATH SERVICES
- ACCESS TO PROPER MEDICALTION AT END OF LIFE (FOR EXAMPLE, TRANS PEOPLE ARE OFTEN DENIED PAIN AIDS)
- FINDING A SUPPORT TEAM COMFORTABLE IN THE DYING SPACE THAT IS ACCEPTING OF WHO THEY GENUINELY ARE



TRANS DEATHCARE PROBLEM SOLVE

Solutions

EDUCATE THE COMMUNITY

- GET A TENT AT PRIDE, SHOW PEOPLE HOW TO FILL OUT ADVANCE DIRECTIVES, ETC.
- WORKSHOPS AT PLACES OF WORSHIP OR COMMUNITY CENTERS
- RADIO OR PODCAST ADVERTISEMENTS
- INSTAGRAM AND FACEBOOK ADS THAT POINT TOWARD FREE RESOURCES
- HOST WORKSHOPS FOR CHURCHES AND OTHER COMMUNITY GROUPS, ESPECIALLY ONES THAT ALREADY HAVE HIGH-TOUCH PROCESSES AROUND DEATH
- HAVING PEOPLE FROM TRANS COMMUNITY HOLD WORKSHOPS, GIVE TALKS, GO TO CHURCHES, COMMUNITY PLACES, FUNERAL HOMES, ETC. HAVE FAMILY MEMBERS DO THE SAME. THEY MAY BE LISTENED TO MORE EASILY.
- CREATE AN ONLINE RESOURCE FOR TRANS AND NONBINARY DEATHCARE SPECIFICALLY
- TV ADVERTISEMENTS
- ACCESSIBLE EDUCATION RESOURCES AVAILABLE DIGITALLY
- BIODEGRADABLE/CREMATABLE GENDER AFFIRMING PROSTHETICS/GARMENTS
- FREE WORKSHOPS ON HOW TO PREPARE ADVANCE DIRECTIVES, CHANGE LEGAL NEXT OF KIN, ETC.
- REGIONAL INFORMATION PACKETS REGARDING WHERE LEGAL NAMES ARE AND ARE NOT REQUIRED LEGALLY REQUIRED
- LEGAL ADVOCACY FOR MAKING IT EASY TO CHANGE WHO YOUR POWER OF ATTORNEY OR ESTATE GOES TO
- IN THE VEIN OF 'WALKING IN SOMEONE ELSE'S SHOES'... TRAININGS WHERE PEOPLE TAKE TURNS BEING HYPOTHETICALLY OSTRACIZED FOR BEING TALL, RED-HEADED, WEARING RED POLISH, HAVING STRAIGHT HAIR, ETC. TO GET A SLIGHT FEEL FOR BEING JUDGED OVER SOMETHING PERSONAL

EDUCATE MEDICAL PERSONNELL

- ADVOCATING FOR POLICIES SURROUNDING TRANS RIGHTS IN MEDICAL SPACES
- ADVOCATING FOR EDUCATION AS A NECESSARY PART OF MEDICAL CERTIFICATIONS
- ASKING THE MEDICAL COMMUNITY FOR THEIR OWN IDEAS AND SOLUTIONS
- CONTINUING EDUCATION CREDITS FOR TRANS / NONBINARY / ETC TRAINING
- EMBODIED LABS VR EXPERIENCES FOR BUILDING EMPATHY AROUND TRANS/NONBINARY CARE

EDUCATE DEATHCARE PROFESSIONALS

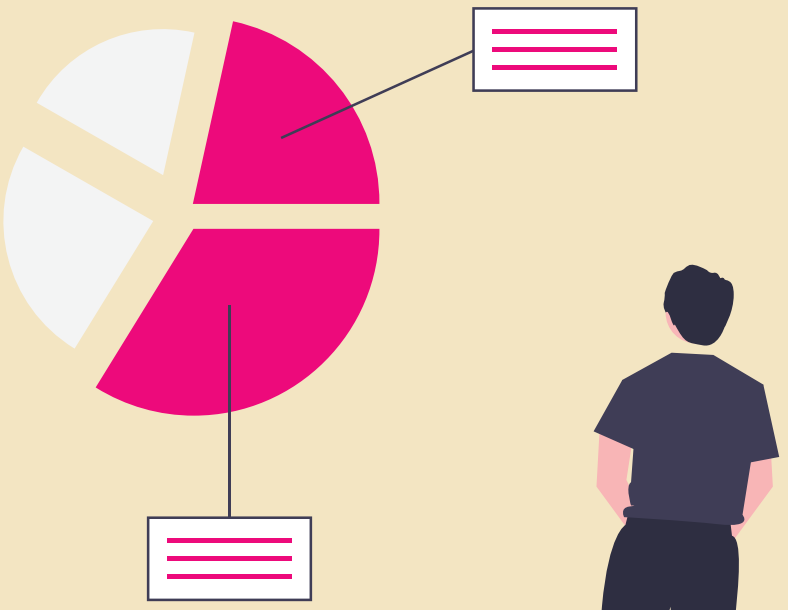
- CREATE AN ONLINE RESOURCE FOR TRANS AND NONBINARY DEATHCARE SPECIFICALLY
- FUNERAL DIRECTOR EDUCATION ON DEADNAMING AND OTHER ISSUES IN QUEER SPACE
- OUTREACH/WORKSHOPS/CONFERENCES

SURVEY

We (Isabel Knight and Eva Ting) are two entrepreneurs in the death-care field who connected via a support network created for those working in the end-of-life (EOL) and deathcare industries. Through participation in a series of design-centered workshops, we recognized a need to learn more about the forces shaping the deathcare space from a quantitative and qualitative data perspective. There seems to be a lack of data on the more progressive death positive and death tech fronts, which have seen an influx of new entrants in recent years. This survey is an initiative to gather some of those insights ourselves and to continue cultivating more understanding of the changes, challenges, and opportunities in the evolving deathcare space.

The survey took place over a two-week period at the end of September 2021 and was mainly disseminated via community groups and affiliations on platforms such as Facebook, LinkedIn, and Slack. With 52 survey respondents, we are not presenting the findings as a representative cross-section of the industry by any means. Contextualized in the demographic data, however, the responses offer patterns and trends worth noting, and the anecdotal and qualitative responses provide helpful insight.

Our hope is that industry-wide surveys such as this will continue to be offered with broader participation and increased engagement, so that data quality can improve and inform opportunities for growth, innovation, and collaboration in the EOL and deathcare industry.

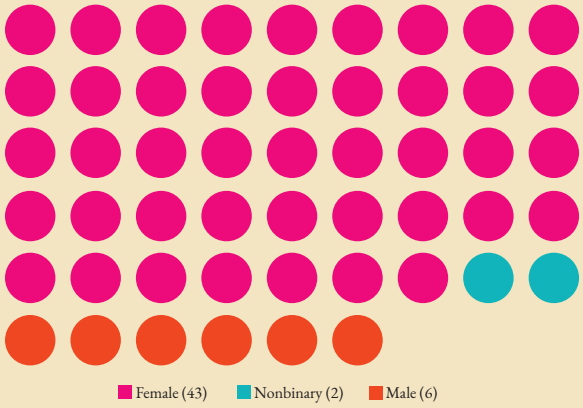


DEMOGRAPHIC DATA

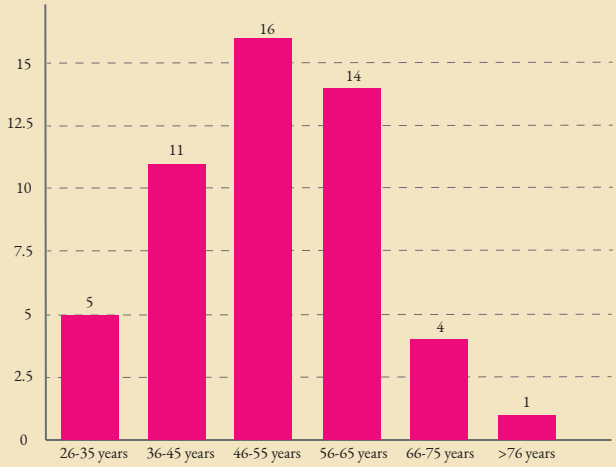
We wanted to understand who is represented in the deathcare space, and though we knew anecdotally who we were seeing take part in conversations around deathcare on the Internet, we wanted to try to confirm that understanding via data.

We asked questions about age, gender, ethnicity and location and found that the respondents were predominantly white women, though we would note that a lot of this is likely also because many of the channels we disseminated the survey through were doula groups.

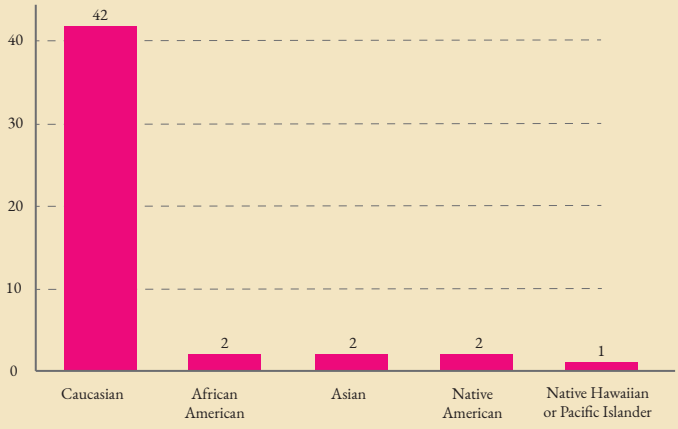
Gender of Respondents



Age of Respondents

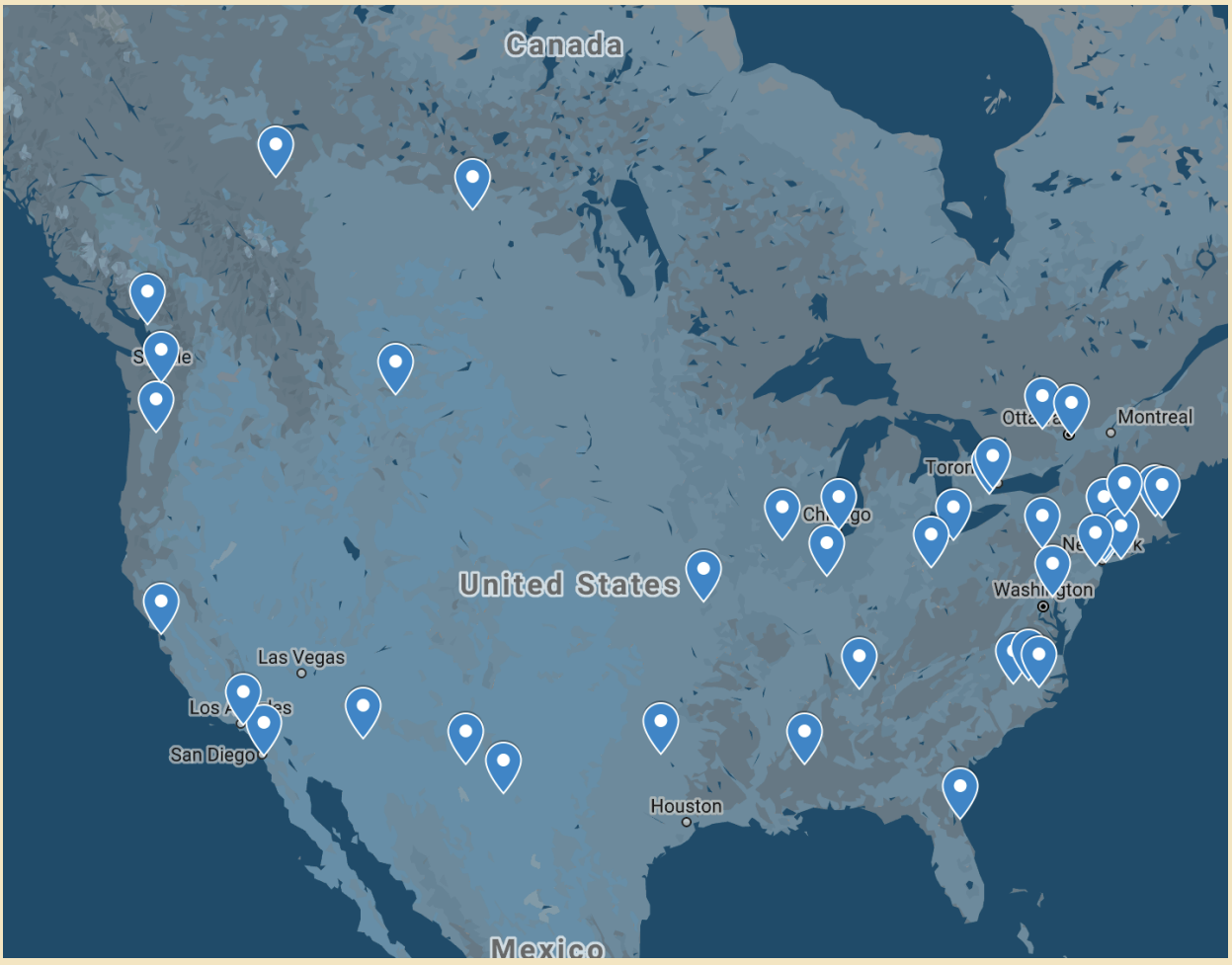


Ethnicity of Respondents



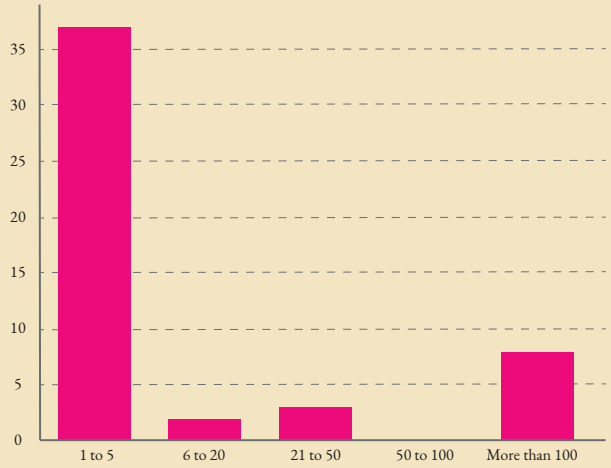
LOCATION DATA

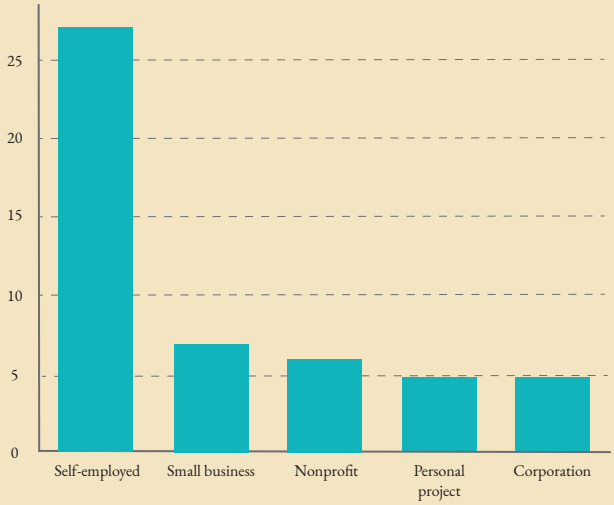
We asked survey respondents where they were located, and they had the option to respond with any level of detail they wanted (town, state, country level, etc.) and we used those responses to plot the approximate location of respondents on the map below. Not shown on this map are 2 respondents who reside in the United Kingdom.



BUSINESS DATA

Given the number of startups there are in the deathcare space, we wanted to understand more about how businesses are structured and how they are pricing their services and getting clients. Most of the respondents surveyed work as self-employed end of life doulas.





SURVEY QUESTION:
WHAT IS IT THAT YOU DO?

22
END OF LIFE DOULAS

5
ADVANCE CARE PLANNERS

3
CELEBRANTS

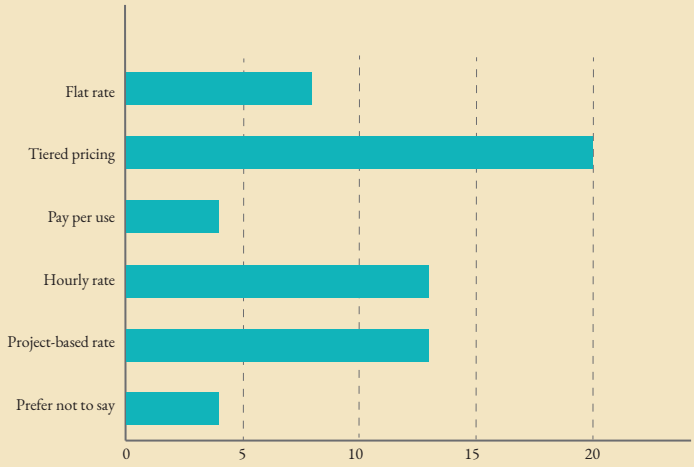
3
SOCIAL WORKERS

17
OTHER

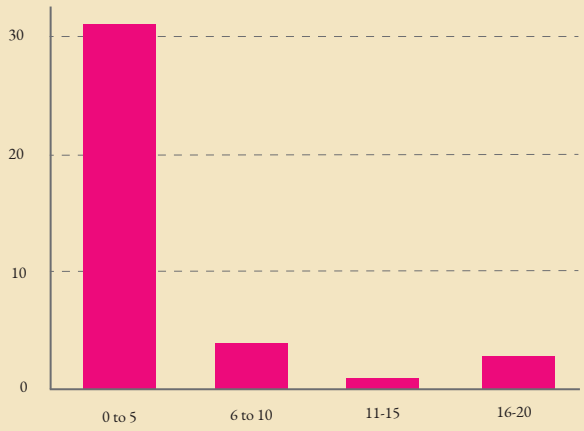
FUNDING AND PRICING

We found that given the number of deathcare professionals who were self-employed in the sample, most were self-funded, have been in the industry for less than five years, and utilized a tiered pricing system. Though many do have their deathcare job as their main souce of revenue, most work in an unrelated or deathcare-adjacent job and do deathcare work on the side.

Pricing Structure

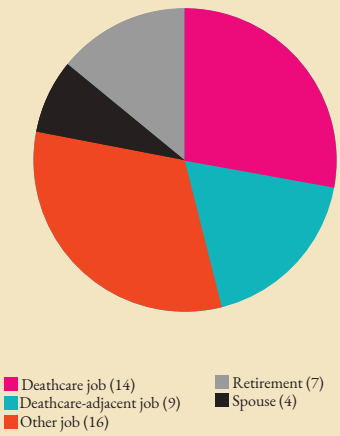


Years in Industry



Primary Funding Source

Main Source of Revenue



MARKETING

The results from our survey's ranking questions were determined by using a weighted average. For example, when reviewing each member's response, the selection ranked first was multiplied by three, the selection ranked second was multiplied by two, and the selection ranked third was multiplied by one. In this way, we have ranked the responses of the community as a whole.

SURVEY QUESTION:
WHAT ARE THE TOP WAYS YOUR CLIENTS CURRENTLY FIND YOU?

Rank	
1	Referrals
2	Family and friends
3	Social media
4	Advertising (print and digital)
5	Partnering businesses/organizations
6	Directories

SURVEY QUESTION:
IDEALLY, HOW WOULD YOU LIKE TO REACH NEW CLIENTS? RANK 1-3, 1 BEING THE MOST PRODUCTIVE.

Rank	
1	Referrals
2	Family and friends
3	Partnering businesses/organizations
4	Advertising (print and digital)
5	Social media
6	Directories

INDUSTRY INFLUENCES

Patrticipants felt that the biggest influences in the deathcare space were the death positive movement and the COVID-19 pandemic, with affordability and environmentalism ranking further down on the list but still maintaining a strong priority for many. In terms of what respondents felt would help their practice the most, there was a split between greater collaboration opportunities and support in finding more clients.

SURVEY QUESTION:
WHAT DO YOU SEE AS THE BIGGEST FORCES SHAPING THE DEATH CARE INDUSTRY RIGHT NOW? RANK THE TOP THREE, 1 HAVING THE MOST IMPACT.

Rank	
1	Death positive movement
2	COVID-19
3	Accessiblity/affordability
4	Environmentalism
5	Religious practices and secularization
6	Gender issues

SURVEY QUESTION:
FROM THE FOLLOWING, PLEASE RANK THREE THINGS THAT WOULD MOST POSITIVELY IMPACT YOUR WORK IN THE EOL/DEATHCARE INDUSTRY, WITH 1 BEING MOST BENEFICIAL.

Rank	
1	Opportunities to collaborate with other EOL/deathcare vendors and service providers
2	Support and resources to reach more customers
3	Ongoing training and education on best practices in EOL/deathcare
4	Broader EOL education for the general public
5	Resources to address disparities in death-care (ex. socioeconomic, racial, LGBTQ+, trans and gender diverse, etc.)
6	Resources and training for green deathcare and environmental sustainability
7	Legal advocacy on the the state/local/federal level

CHALLENGES

Most of the challenges mentioned in the survey responses fell into two main themes: lack of resources, and lack of education or awareness among the general public of deathcare issues.

After those main challenges, a few respondents also mentioned the pandemic, social inequities in deathcare amongst vulnerable populations such as the disability community and people experiencing homelessness, and a culture of fear around death that prevents potential clients from having important conversations around their own death and the death of loved ones. Below is a representative sample of quotes from each theme, some of which may have been lightly edited for clarity.

SURVEY QUESTION:
WHAT ARE THE MOST PRESSING CHALLENGES FACING YOUR WORK?

LACK OF RESOURCES

19 Respondents

> Figuring out how to live out my purpose in an era of out of control cost of living.

> Having enough time to devote to clients, setting boundaries, and working with family members who haven't been involved in patient care.

> Having money to do more work and reach more people

> Lack of funds to begin a brick and mortar hospice

> Can't keep up with client demand

LACK OF EDUCATION AND AWARENESS

11 Respondents

> Educating the public about what we do and why there is value to our work.

> Lack of clients and lack of recognition from the medical industry

> Living in a remote area and lack of knowledge and understanding of what doula work is.

PANDEMIC 4 Respondents

> Unpredictability due to covid surges make it hard to plan, hire, and retain talent.

> Covid and it's divides in affordability.

2 Respondents **DEATH STIGMA AND CULTURE OF FEAR**

> Living in a death averse culture.

> Fear from potential clients.

INEQUITIES 2 Respondents

> Exclusion of the disability community. Not being a part of the conversations when it comes to education.

> People experiencing homelessness need more support.

SURVEY CONCLUSION

As is true for any interesting data, the survey brought up even more questions that could be explored in the future in other surveys or via other research methods.

For example, when we asked "Who would you turn to in your time of need if you were to face a death personally," many of you responded with the rich sources of community support we can only hope everyone the general public would be able to access in the future. You mentioned doulas, hospice, the queer community, family, other members of the deathcare community, and more.

As people who work in this industry, we are more likely to know someone who could help them in the event of a death. We would love to have more consumer-focused data on the extent to which the experience of the average person who may never have heard of the death positive movement or have any interest in deathcare may differ.

This particular survey also featured a lot of end of life doulas because many of the groups we posted the survey in were doula groups, but we would love to explore other groups in the deathcare ecosystem, such as death tech startups and traditional funeral establishments (such as funeral directors, crematory operators, and cemetery owners), We would also like to better understand the particular needs of communities such as the LGBTQ+ or indigenous communities.

Our hope is this report can serve as a reference point, both for future research and to inform your current work with your businesses, nonprofits, and communities. Through sharing such research results, we hope to empower better deathcare spaces for all communities and make efforts to include people who may not be represented here.

WHERE DO WE GO FROM HERE?

We hope that you can take these findings and run with them, to inform the business you do, the nonprofits you run, and the community groups you lead. We want to empower you to design better deathcare spaces for your communities and make efforts to include people who may not be represented here.

Our hope is this report can serve as a reference point, both for future research and to inform your current work with your businesses, nonprofits, and communities. Through sharing such research results, we hope to empower better deathcare spaces for all communities and make efforts to include people who may not be represented here.

We hope you find this analysis helpful, and if you would like to offer any feedback on things like how the survey was conducted, the kinds of questions you would like to see asked in the future, or anything else relating to the survey, please reach out to us!

If you would like to collaborate on a survey in the future, we are also very open to collaboration.

You can email Isabel at isabelxknight@gmail.com, Eva at hello@heretohonor.com, and Nix at phoenixvkelley@gmail.com.

APPENDIX

Links to relevant online whiteboards used to create the raw data for this report:

Death Designer Workshop Miro Link

Links to separate PDFs for the maps included in this report:

Deathcare Stakeholder Map

Medicalized Death Journey Map

Nonmedicalized Death Journey Map

Links to learn more about the contributors to this report:

Death Designer Website

Here to Honor Website

Link to view the original survey:

Original Survey Link