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Narrative medicine and death in the ICU: word clouds as a visual legacy

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ABSTRACT

Objective The Word Cloud is a frequent wish in the 3 Wishes Project developed to nurture peace and ease the grieving process for dying critically ill patients. The objective was to examine whether Word Clouds can act as a heuristic approach to encourage a narrative orientation to medicine. Narrative medicine is an approach which can strengthen relationships, compassion and resilience.

Design Word Clouds were created for 42 dying patients, and we interviewed 37 family members and 73 clinicians about their impact. We conducted a directed qualitative content analysis, using the 3 stages of narrative medicine (attention, representation, affiliation) to examine the narrative medicine potential of Word Clouds.

Results The elicitation of stories for the Word Cloud promotes narrative attention to the patient as a whole person. The distillation of these stories into a list of words and the prioritisation of those words for arrangement in the collage encourages a representation that did not enforce a beginning, middle or end to the story of the patient's life. Strong affiliative connections were achieved through the honouring of patients, caring for families and sharing of memories encouraged through the creation, sharing and discussion of Word Clouds.

Conclusions In the 3 Wishes Project, Word Clouds are 1 way that families and clinicians honour a dying patient. Engaging in the process of making a Word Cloud can promote a narrative orientation to medicine, forging connections, making meaning through reminiscence and leaving a legacy of a loved one. Documenting and displaying words to remember someone in death reaffirms their life.

INTRODUCTION

The intensive care unit (ICU) can be a de-humanising environment for patients, their family members and clinicians.[1–3] Barriers to humanisation include the dominance of medical technology and invasive devices, patients' altered consciousness and their inability to exercise choice.[1] Family members have reported the ICU to be more frightening than a general ward, describing it in one study as 'a nightmare' or 'a prison'.[3] In this stressful work environment, clinicians who care for dying patients may suffer themselves from compassion fatigue, vicarious traumatisation and burnout.[2]

Narrative medicine is one approach that can be used to forge and enrich human relationships in the ICU.[4 5] Narrative medicine is a model of humane care, where clinicians recognise, absorb, interpret and are moved by patients' stories.[5] A combination of mindfulness, observation and sharing of self permits the clinician and patient to recognise their common humanity.[6] The ultimate goal of narrative medicine is 'affiliation'—that is, a strong connection between human beings, or within the self.[6 7] Narrative medicine aims to benefit both patients and clinicians. Patients may benefit from empathic therapeutic relationships with clinicians committed to providing individualised care. Clinicians may benefit from finding a way to be 'buoyed by the extraordinary courage, resourcefulness, faith and love they behold every day in practice', which may enhance their resilience to the suffering they encounter in practice.[4]

In this report, we explore the contribution that a narrative orientation to medicine can make to end of life care in the ICU. We describe a heuristic approach to promote a narrative orientation—the creation of 'Word Clouds' for dying patients. We draw on our creation of

Word Clouds as part of the 3 Wishes Project (3WP). The 3WP is an ongoing programme founded in the ICU of St Joseph's Healthcare in Hamilton, Ontario, Canada.[8 9] This project was developed with the objectives of bringing peace to the final days of critically ill patients, and to help family members in grief. The 3WP achieves these objectives by soliciting a set of three or more wishes from dying patients and their families. The wishes are focused on helping a patient die with dignity and bringing comfort to the patient and family. Through implementing these wishes, the project aims to counter the technologically intense, de-humanising aspects of the ICU, benefitting patients, families and clinicians through enhanced human connection at a time of grief and existential crisis.[8 10]

Word Clouds were initially conceived as a gift to the family, as a way of coming to know and honouring the patient and family. While we initially hoped this gift would be meaningful, we came to recognise that it can be much more than that, powerfully effecting the relationships among patients, family members and clinicians. Here, we examine the effect of Word Clouds through the lens of narrative medicine, using the three stages of narrative medicine (attention, representation, affiliation) as a framework to understand the process and potential impact of Word Clouds. The objectives of this study are to describe how Word Clouds foster a narrative medicine orientation, and through qualitative formative evaluation, document the impact of Word Clouds from the perspectives of families, clinicians and the project team.

The process for creating Word Clouds

A Word Cloud is a graphic representation of words, concepts and phrases associated with a patient. The resulting collage is a form of art—a 'Picture of Words' (figure 1). We use wordle.net to create Word Clouds, although there are many free word cloud creators available online. Ten steps to creating Word Clouds are outlined in online supplementary appendix A. The process of creating Word Clouds, 'making visible and audible that which otherwise may pass without notice'[6] involves iteration between the narrative steps of attention and representation, supporting all involved in achieving the ultimate goal of narrative medicine: affiliation—authentic connections between others and the self.[7] While the process of creating Word Clouds can deepen affiliative relationships, relationships are a precondition for this work.

Word Clouds are created and delivered through collaboration between the 3WP team, ICU clinicians involved in the care of the dying patient and the patient's family. The 3WP team is an interdisciplinary group of ICU clinicians, researchers and trainees (research and clinical). Many different ICU clinicians become involved with the 3WP when one of their patients is enrolled.

Word Clouds are usually a wish of the clinical team for the family. We typically enrol one or two patients a week in 3WP, and have created Word Clouds for about 40% of these patients and families. The process of making Word Clouds can happen in a variety of ways, usually organised by one of the 3WP team members. Depending on who is involved, words are elicited directly or indirectly by clinicians, or directly generated by family members. When clinicians or 3WP team members elicit words directly, the idea of the Word Cloud is explained, an example is shared, and then if the family is interested, a further conversation ensues about their loved one. Words are recorded that reflect the characteristics, passions, hobbies and stories that they share. In some instances, the Word Cloud is reprinted a few times, incorporating serial feedback and additional words offered by family members and friends. When words are elicited indirectly, it is usually prompted by a family encounter filled with stories and memories of the patient. The 3WP team members and clinicians brainstorm a list of words about the patient, then return to the family to explain the idea of the Word Cloud and show them a list of initial words. The 3WP team then works with the family to expand the list, or leaves the list with the family for them to work on together. Sometimes

Figure 1 Sample word cloud.

the Word Cloud is developed by the 3WP team as a surprise for a family, after working together with the patient's clinical team to share collective knowledge of the patient. Sometimes, after a family hears about Word Clouds, they choose to create the list on their own, often waiting until others have gathered so they can brainstorm words and share stories together. In other instances, family members may individually write down words and pass the list to other family members or friends, then return their list to the 3WP team for creation of the Word Cloud.

METHODS

We employed qualitative and quantitative methods as described elsewhere.[8] Briefly, following informed consent and research ethics approval, we conducted semistructured interviews with family members of patients, inviting them by telephone 1–6 months postmortem. We also conducted semistructured interviews with clinicians who worked with enrolled patients, purposively sampling clinicians caring for the patient in their past 72 hours inviting them via email 1–2 weeks postmortem. Interviews focused on the project's influence on the dying process, and the impact of the wishes, including Word Clouds. Aligned with objectives of this study, findings for this analysis were focused on the phenomenon of Word Clouds; we included data from family members and clinicians who discussed experiences related to Word Clouds. Interviews were digitally recorded, transcribed verbatim and anonymised. We also included data from field notes of seven project members involved in creating Word Clouds. Qualitative content analysis was used to analyse the data, using the stages of narrative medicine (attention, representation, affiliation) as the coding frame.[11]

RESULTS

To date, 100 patients have been enrolled in the 3WP, 42 (42%) of whom have received Word Clouds as a wish (table 1). We conducted interviews with 37 family members (table 2) and 73 clinicians (table 3) involved in the final days of the lives of patients who received Word Clouds. Most Word Clouds represented antemortem wishes (22, 52.4%) offered as gifts to families while their loved one was in the ICU; some were postmortem (20, 47.6%), offered to families when they returned to the hospital for interviews.

Creating and sharing Word Clouds encourages a narrative orientation to medicine. Building Word Clouds requires attention to and representation of the patient's identity as a person, beyond their medical condition or disease state. This narrative-building process strengthens affiliations among family members, clinicians and the patient, providing much needed comfort to the grieving family members.

Table 1 Patient characteristics (N=42)

Baseline characteristics	
Age in years at death, mean (SD)	67.5 (17.3)
Female, n (%)	15 (35.7)
Race, n (%)	
White	39 (92.9)
Non-white	3 (7.1)
APACHE II score, mean (SD)	28.0 (8.7)
ICU admitting diagnosis, n (%)	
Cardiovascular/vascular	19 (45.2)
Respiratory	10 (23.8)
Gastrointestinal	5 (11.9)
Neurological	4 (9.5)
Sepsis	2 (4.8)
Metabolic	1 (2.4)
Other surgical	1 (2.4)
Spiritual belief, n (%)	
Agnostic	5 (11.9)
Anglican	3 (7.1)
Baptist	3 (7.1)
Catholic	16 (38.1)
Christian	1 (2.4)
Lutheran	2 (4.8)
Presbyterian	1 (2.4)
Protestant	2 (4.8)
Unitarian	1 (2.4)
United	1 (2.4)
Unknown	3 (7.1)
None indicated	4 (9.5)
Exposures and events in the ICU	
Advanced life supports administered at any time in ICU, n (%)	
Mechanical ventilation	42 (100.0)
Inotropes	26 (61.9)
Dialysis	14 (33.3)
Days from ICU admission to death, median (IQR)	9 (4–24)
Days from hospital admission to death, median (IQR)	13.5 (6–50)
Received mechanical ventilation at any time in ICU, n (%)	42 (100.0)
Received inotropes at any time in ICU, n (%)	26 (61.9)
Received dialysis in ICU (not receiving it prior to ICU), n (%)	7 (16.7)

ICU, intensive care unit.

Narrative attention through word elicitation

Creating Word Clouds requires a list of words that capture the essence of each patient. Eliciting these words is an opportunity to share stories with patients and their loved ones. We invite families, patients and loved ones to tell stories about the patient—experiences, events, attributes, activities, passions and people important to them:

> It was a really nice surprise because [Physician] didn't tell us she was giving that …she had very gently extracted the information out of myself and my cousin's wife. We had sat and had a talk with her, just

Table 2 Family member characteristics (N=31)

N=31 Interviews	
Days from patient death to interview, median (IQR)	70 (33–117)
Interview type, n (%)	
Face-to-face	24 (77.4)
Email	1 (3.2)
Phone	6 (19.4)
N=37 Family members interviewed	
Relationship to patient, n (%)	
Spouse	4 (10.8)
Partner	2 (5.4)
Friend	2 (5.4)
Sibling	5 (13.5)
Parent	4 (10.8)
Child	15 (40.5)
Other (son-in-law, daughter-in-law, nephew, niece)	5 (13.5)
Age, mean (SD) years	55.6 (12.9)
Sex, n (%)	
Female	23 (62.2)
Male	14 (37.8)
Spiritual affiliation, n (%)	
Agnostic	4 (10.8)
Anglican	3 (8.1)
Baptist	3 (8.1)
Catholic	11 (29.7)
Christian	4 (10.8)
Protestant	1 (2.7)
United	1 (2.7)
None	7 (18.9)
Unknown	3 (8.1)

Table 3 Clinicians characteristics (N=73)

Days from patient death to interview, median (IQR)	11 (4-22)
Interview type, n (%)	
Face-to-face	71 (97.3)
Email	1 (1.4)
Phone	1 (1.4)
Profession, n (%)	
Physician	35 (47.9)
Nurse	22 (30.1)
Spiritual care clinician	5 (6.8)
3 Wishes research staff	2 (2.7)
Physiotherapist	1 (1.4)
Social worker	1 (1.4)
Respiratory therapist	4 (5.5)
Other (ethicist, medical student, chief executive officer)	3 (4.1)
Age, mean (SD) years	36.2 (12.1)
Sex, n (%)	
Female	42 (57.5)
Male	31 (42.5)
Spiritual affiliation, n (%)	
Agnostic	9 (12.3)
Anglican	6 (8.2)
Baptist	2 (2.7)
Catholic	11 (15.1)
Christian	12 (16.4)
Jewish	1 (1.4)
Muslim	8 (11.0)
Spiritual	6 (8.2)
United	1 (1.4)
Unknown	1 (1.4)
None indicated	9 (12.3)
Other	7 (9.6)
Years working in critical care	
Median (IQR)	2 (0.4–12)
Mean (SD)	7.8 (10.8)

> the two of us…she asked us just, you know, general information without me even realizing it, she got it all out…that was really perceptive of her and it was a very wonderful gift. (Daughter)

Clinicians enjoy this opportunity to connect with the patient and family:

> That's been kind of fun just hearing them…or just really laugh about stuff…gives us an opportunity to connect a little bit…a privilege in itself, to be part of the moment, to just elicit those words that are meaningful to them. (Respiratory therapist)

Clinicians perceive these conversations as beneficial to families: "to be able to reflect on him and talk about their memories of him and have a few good laughs and a few good cries" (nurse).

Sometimes family members compile the words themselves, often choosing to wait until other family members have gathered so they can tell stories as they generate the list together.

> A chance to be preoccupied with something else other than what was actually going on…it was more of a family bonding in time of need and your heart hurts but it's nice to talk about something that brings a smile on your face. (Daughter)

Word Clouds provide a mechanism to allow the 'person' to return to focus, eclipsing the 'patient'. The exercise helps people to remember what was special about the person: "once we started brainstorming the words, I mean, it brought back a lot of different memories of different times past" (son).

Clinicians reflect on the privilege of participating in these intimate conversations about their patients. Atypical in practice, such moments can strengthen clinicians' commitment to their vocation:

> It takes us from being detached to being engaged. It is often a means of reaffirming why it is we do the work we do. The Word Clouds can provide an outlet for our compassion and give us strength to continue to do the work we do. (Project team member)

Trainees note how Word Clouds taught them not to lose sight of their patient as a person: "if you can bring it back to who they were, that is obviously much more important than what the disease process was" (resident).

Word Clouds are instructive even to clinicians who are not involved in their creation: "I think as a clinician, not knowing the patient that well, when you look at that [Word Cloud] you have a completely different understanding of them" (resident). Word Clouds can be a starting point for conversations. A resident explains how Word Clouds helped him understand the motivations of a patient wishing for access to email and Skype in the ICU:

> It really opened up the opportunity to talk about a number of these things that I have never known about her and it gave me the opportunity to get to know her a bit better which helped me, again, to understand where she was coming from and why her desires were what they were. (Resident)

Narrative representation through Word Cloud creation

'Narrative representation' refers to the act of retelling information. Clinicians are experienced in certain types of oral representation (eg, case summaries on rounds), and written representation (eg, medical charts and consultation letters).[7] Word Clouds allow clinicians and families to represent the patient collaboratively, using the particulars and priorities of the patient rather than the imperatives of practice. Generating the words involves keen attention to the individual: "they started to remember things about the patient and talk about the significant relationships and significant things in his life and who he was and what these words represented" (nurse).

After distilling the stories into a list of words and phrases, the next task is to prioritise those phrases to decide what will appear in larger, bolder fonts. This representative act requires attention to the significance of various words. Prioritising the words can strengthen family bonds: "it was a chance for us to just share our stories and pick the most important words that we thought were important to him. Or to us…Each one of the kids got to pick their words, like, his grandchildren and they all told a story in regards to why they picked that word" (daughter).

Word Clouds facilitate the telling of multiple stories, inviting interpretive flexibility not possible with a single narrative story. Word Clouds are a conversation piece, prompting reminiscence. "A word can mean quite a bit. Every word can have a story, just one word itself…Or multiple stories, depending on who's looking at it, what your experience with that was" (son).

Also unlike a linear narrative story, a collage of words enforces no beginning, middle, or end to the story of a life. The 3 Wishes Team made this choice deliberately, to celebrate the person and recognise multiple facets of a person's identity:

> I think when the grandkids came in and saw it, it really affected them to see that. Like, you don't look at your Mom as a friend or a person that goes to all these different things, so that really opens it up as to who she was—more than just my Mom. (Daughter)

Finally, the Word Cloud format is more easily accessible to others than a written story. It can be reproduced, displayed publicly, allowing all present to read, study and reflect. It allows viewers to get to know the person better: "His friends have looked at it and said 'Oh, look, my name's on there' or 'Remember this?'" (mother).

Narrative affiliation through sharing Word Clouds

'Narrative affiliation' strengthens connections between people, or within the self. Attention to, and representation of, the person leads to stronger connections among people as they bear witness to the patient's life and death, together confronting the prospect of mortality.

> It is such a privilege to be a part of the patient and family journey, to be invited to be present when they are grieving, crying, praying…While eliciting words you can see the wall break down after spending some time with her, getting to know her son. Allowing her a safe place to grieve for her son. She was no longer alone. (Project team member)

Clinicians' familiarity with patients promotes affiliation. Many family members spoke of their appreciation for the time clinicians took to get to know their loved one as a person, rather than just a patient. "It shows that the care for the hospital, that, you know, they took the time for the patient" (niece). This care extends beyond the patients to include their loved ones, which may be welcome. As one patient's daughter describes, it is a "little bit easier to know that wow, these people cared. Not just about my Dad but about how we were doing, too" (daughter). Clinicians also valued the affiliation: "it also helped them connect with us and also helped us have a sort of a better appreciation for who he was" (clinical fellow).

Word Clouds helped to strengthen family connections, which may bring comfort as grief is confronted and bereavement begins: "it was a nice gesture to have there so we can sit and talk and begin the grieving process" (son). Many clinicians also commented on their observations of how Word Clouds affected family members:

> I think it just helped ease them into the transition…I think it [Word Cloud] really helped her [Patient's wife] to accept that…his life had been meaningful and he had touched a lot of people. (Nurse)

In part, Word Clouds foster connection by prompting family members to talk explicitly about their love

for the patient "it was very moving when they were doing it…it was very moving to hear his friends say the words" (physician).

Word Clouds strengthen connections with patients even after death. One family member stated: "Our daughter will have it and, you know, that was her brother and she looked up to him and he always took care of her so she can look at that picture and say 'Yeah, you know, this was [Patient's name]'" (mother). In the postmortem interviews, families talked about the continued importance of Word Clouds to help feel close to their loved one: "It is up in my house. Yes, I talk to him in front of it every night. I light a candle. It is right under a picture of [Patient's Name]. I light the candle then I pray. Then I talk to him. I feel him around" (wife).

Many families encouraged the project team to continue using Word Clouds in the future, underscoring the healing power of this gift. At one patient's funeral, family members requested donations to the project in support of Word Clouds for others:

> I thought it was so important and I just wanted to raise money for it so that other people could have what we had…I think that everybody should have something that was meaningful, and to me, it was meaningful because it had my Dad's name, and it had everything about him. It was a project we did together while we were here and everybody, from family to friends helped contribute to it. (Daughter)

Beyond the scope of the project, one family talked about continuing the Word Cloud tradition if another family member was dying: "I bet you my kids would carry that on. I bet you they would. They would bring in a piece of paper, now, if somebody's passing and I know they would carry it on because it was so healing" (sister).

DISCUSSION

The process of creating Word Clouds forges connections between family members, clinicians and team members by engaging them in eliciting stories and reflecting on relationships and life journeys. These stories are the heart of the Word Cloud, illuminating the patient-as-person. Families and clinicians then sort through these stories and anecdotes to assemble a selection of meaningful words to represent the life of the patient, in an attempt to symbolically capture their spirit. This iterative relationship between attention and representation offers the opportunity for project and clinical team members to 'donate the self towards the meaning-making of another'.[7] The affiliative connections catalysed by creating and sharing Word Clouds encourage family members and clinicians to beneficially 'join one another as we suffer illness, bear the burdens of our clinical powerlessness, or simply together, bravely contemplate our moral limits on earth'.[6] Word Clouds remain a visual reminder of the coming together of family, friends and clinicians in a time of great pain to honour the patient.

Families

For families, creating Word Clouds provides a mechanism to reframe challenging deaths by remembering the whole person. Focus on the patient-as-person provides dignity,[12] by maintaining a focus on personhood in spite of the 'disintegrating forces of illness and the alienating aspects of late-industrial healthcare systems'.[13] Word Clouds provide an alternative focus for time spent in the ICU, engaging families to reminisce about shared experiences, make meaning about a life and identify the patient's legacy. In this way, Word Clouds offer a gentle entrance into grief and bereavement. This simple encouragement of authentic communication at the end of life can benefit both the patient, when capable, and family members, helping them assign meaning to the experience, and providing an opportunity for healing.[14] By finding words to remember someone in death, this reaffirms their life.

The elicitation of words echoes some aspects of reminiscing as a technique in grief therapy. Word Clouds provide a guided opportunity for families and friends to reflect together on certain moments as a way of processing and integrating them into memory. Shared reminiscence provides social support to those participating,[15] and can function as a grief ritual, leading to emotional catharsis and acceptance of the transition.[16] Reminiscence helps integrate ideas of the past with plans for the future, retaining connections with the deceased through memory.[15] Beyond the elicitation of words, completed Word Clouds serve as a visual catalyst for future reminiscing, alone or collectively.

The work of reminiscing, sharing stories and memorialising the patient in Word Clouds contributes to building a legacy for the patient. A legacy is "an aspect of the self that remains in the world after death…the sum total of the life we have lived".[17] Legacy work involves two essential aspects of spirituality—a sense of meaning and purpose, and transcendent connections; hence, legacy building affirms meaning within a person's life and the value of the life lived, and also affirms connections that transcend death. Creating Word Clouds provides an opportunity for legacy building by encouraging loved ones to elaborate on features of personhood, therein giving meaning to a life. Completed Word Clouds are a touchstone for mourning families to remember the deceased as they navigate their own individual grief trajectories.[18]

Clinicians

For clinicians, the process of creating or viewing Word Clouds can shift perspective from detachment to engagement.[4] Eliciting words allows clinicians to

work together on a task and see a family make peace at a time of incomparable pain, while recalling positive memories. It is a way for clinicians to tangibly show family members that they want to help honour the patient. Also, this narrative orientation to medicine may help clinicians exhibit exquisite empathy, defined as 'highly present, sensitively attuned, well-boundaried, heartfelt empathic engagement'[19] which invigorates rather than depletes clinicians. The connections formed through offering something meaningful to patients and families may also promote 'compassion satisfaction', or pleasure derived from the work of helping others which may counterbalance compassion fatigue to encourage resiliency.[20]

Word Clouds have become a valued ritual for clinicians in our ICU. The project team receives frequent requests to create them. The narrative act of telling and listening to stories, and of generating words for Word Clouds has become a personalised, ritualised act, "crafted to support and serve those who are in need at the present moment…their value is measured in how much healing, connection and meaning they deliver to the participants".[21] Creating a Word Cloud encourages healing connections among family members, clinicians and patients.

Strengths and limitations

This study describes the strong potential for positive impact with an inexpensive, easy to implement process to encourage a narrative orientation to medicine. This research involved a large number of participants for a qualitative study, rendering the results credible and trustworthy. Transferability to other settings remains unexplored, as this project is established in one ICU in St Joseph's Healthcare in Hamilton, Canada, and is developing in other centres.

CONCLUSIONS

Creating Word Clouds is an integral aspect of the 3WP, and serves as a tangible example and visual display of a wish. Word Clouds honour the personhood of patients, as a symbolic embodiment of a life lived. Creating Word Clouds represents a process of both grief and healing, encouraging a narrative approach to medicine which creates a forum for reflection for the family, and encourages clinicians to see beyond the medical status of the patient. As a completed product, Word Clouds give the family a memento of their loved one to keep and cherish, contributing to the patient's legacy that lives on after death.

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