



Dialysis Organization Online Information on Kidney Failure Treatments: A Content Analysis Using Corpus Linguistics

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Rationale & Objective: Dialysis organizations' websites may influence patient decision making, but the websites have received almost no consideration. We investigated how/whether these websites present all kidney replacement therapy options and how the quality of life of these options is portrayed.

Study Design: Content analysis using corpus linguistics (computer-assisted language analysis).

Setting: Website content aimed at patients from the 2 major dialysis organizations' websites, totaling 226,968 words. The analysis took place from November 12, 2020, to March 30, 2021.

Analytical Approach: We used linguistic software (AntConc) to document the frequencies of words needed to present treatment options and quality of life information.

Results: Over both sites, dialysis mentions outstripped transplantation mentions. Organization A did not appear to reference conservative kidney

management. Organization B mentioned dialysis more often than conservative management, at a ratio of 34:1. Organization A did not attribute symptoms to dialysis, whereas organization B had 12 mentions of dialysis-induced symptoms out of 87 total symptom references. Both organizations framed life on dialysis optimistically, suggesting that patients can continue to engage in "work," "sex," or "travel"; organization A referenced sex, work, and/or travel 123 times and organization B referenced these 262 times.

Limitations: We used quantitative analysis and linked ideas with certain keywords. We did not conduct a detailed qualitative inquiry.

Conclusions: The websites emphasized dialysis as a treatment for kidney failure, and the quality of life on dialysis was framed very optimistically. Qualitative studies of treatment modalities and the quality of life on dialysis in the patient-targeted material of dialysis organizations are needed.

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Persons receiving maintenance dialysis are not homogenous; for some patients, dialysis is a bridge to transplantation, but for others, dialysis is the destination therapy.¹ Both in terms of costs and patient outcomes, kidney transplantation is a superior form of kidney failure

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treatment.² However, the largest population living with kidney failure is the elderly³; these patients often have multiple comorbidities⁴ and are often ineligible for kidney transplantation. Therefore, they are left with the choice between 2 remaining treatments, conservative kidney management (CKM) or dialysis. Of these options, dialysis is often presented as the default treatment option.⁵ Yet, particularly for the elderly with multiple comorbidities, some studies suggest that dialysis confers no significant survival benefit whatsoever,⁶ whereas other studies suggest a modest life expectancy gain.^{7,8} Dialysis can be associated with a high prevalence of debilitating symptoms, steadily declining functional ability, increased mental health issues, commitment to continued health care use, and increased hospitalizations.⁹⁻¹¹ Therefore, in some cases, CKM may align well with patient preferences,¹² and so, for true goal-concordant and fully informed decision making to occur, the discussion of CKM is necessary.¹³

Clinicians have the ethical responsibility of discussing dialysis outcomes with patients,¹⁴ and provider discussions are patients' preferred sources of information.¹⁵ Yet goal-concordant and informed decision making seldom occur for patients choosing kidney replacement therapies¹⁶ because, in part, nephrologists infrequently receive communication and decision-making skill training.^{17,18} Furthermore, communicating that, in certain cases, dialysis may not extend life expectancy is not easy, conceptually or emotionally, for patient or provider.¹⁹ Even when such conversations do occur, they can have lowered efficacy if prior patient misunderstandings have been shaped.²⁰ Thus, calls for studies on how patients make decisions from a variety of inputs have been made.^{15,21,22} Such calls are consistent with the literature across disciplines—in linguistics,²³ medicine,²¹ and communications²⁴—which suggests that patients and people in general create and shape understandings and misunderstandings of their worlds based on what is read, heard, and seen in a variety of circumstances across time.

One of the places that patients and their loved ones may find information is online. A recent survey of patients receiving dialysis and transplant reported that 57% described consuming health information on the internet at least twice weekly.²⁵ The study further pointed out that when seeking information, the patients were more likely to turn to news media over official institutional sites. It is

PLAIN-LANGUAGE SUMMARY

Patients make kidney disease treatment decisions based on a variety of factors and information sources. Dialysis organizations produce extensive websites, yet little research has considered the content of these widely read sites. We wanted to find out if dialysis organization websites portrayed all treatment options available for kidney failure and how those options were presented. We used corpus linguistics (computer-assisted language analysis) to find and count words linked to key concepts. We found that one website did not present conservative management—treatment without dialysis—as even a potential option. Both websites portrayed a very optimistic quality of life on dialysis. It is important that patients understand all their treatment options; more communication training for nephrologists is needed.

potentially troublesome that some patients may not be vetting the authorship, accuracy, and possible bias of the materials that they access. Even so, little research has looked into dialysis organization patient information; most research to date has focused on dialysis decision aids produced by not-for-profit entities.²⁶ Therefore, given the possible relevancy of unofficial sources of information, we analyzed dialysis provider patient-targeted educational materials. Specifically, we asked, do dialysis organizations' online patient educational materials give representation to all kidney failure treatment modalities and their possible pros and cons? To answer this, we used content analysis and computational approaches to linguistics to examine how the materials may color components of informed decision making such as the presentation of all possible treatments, life expectancy information, and the quality of life (QoL).¹³

METHODS

Data Sources

The 2 major US dialysis organizations have a tremendous reach; this study reviewed their online patient educational materials. Organization A serves 205,000 patients at 2,795 US dialysis centers, and organization B serves over 190,000 patients at 2,400 US facilities. A website traffic estimator (semrush.com) estimates that the sites of these 2 organizations receive a substantive number of visitors; in January 2021, organization A received an estimated 2.3 million visitors, and in the same month, organization B received an estimated 598,900 visitors.

Both organizations' websites are expansive with information on a wide variety of topics; our analysis included all pages from both organizations deemed to be aimed at informing patients about treatment and/or QoL. Such materials were titled on the websites as "education," "about

kidney disease," "treatments," "resource center," and "life on dialysis." Other types of information, such as information "for physicians," "careers," "advertisements," and website menus, were excluded. Both webpage text and downloadable materials (PDFs) were included, text from videos was excluded, and links to third party sites were also not included. The total number of words analyzed was 78,713 for organization A and 148,255 for organization B. The analysis occurred from November 12, 2020, to March 30, 2021. Because the study was solely based on patient educational materials and there were no human participants, the study was determined to be exempted by the institutional review board of Mount St Joseph University, Ohio.

Analysis Procedure

Given that the 2 major dialysis provider websites have received little consideration to date, we selected an approach—content analysis—that would allow us to objectively catalog words present and not present in our texts and make inferences about the existence of associated meanings.²⁷ We implemented our content analysis in a straightforward, objective way. First, to reduce the likelihood of bias, before any analysis of the data began, based on prior literature^{13,28} and ethical framework,^{19,29} we determined which ideas may be needed to support informed decision making: transplantation information, presentation of CKM as a potential dialysis alternative, life expectancy, and QoL information.^{13,19} The linguist, according to the established linguistic research methods, mapped relevant ideas to words that would have to be present in the text to express said ideas.³⁰⁻³² Then, the words under study were extracted using the software AntConc.³³ Finally, counts for each word were tallied; both absolute and relative frequencies (words per 1,000) are reported. It should be noted that our statistics are descriptive and not inferential because the study sampled all relevant pages; such an approach is consistent with content analysis.²⁴

Table S1 presents the analysis procedure in further detail, showing which words were mapped to which concepts. This approach is underpinned by a linguistic theory called systemic functional linguistics³²; that is, in certain instances, it can be possible to determine the likely existence of certain concepts based on the absence or presence of words that must usually be present to express those concepts. For instance, to express time, in the context of how long one might live on dialysis, in most cases a time measure word like "year," "month," "time," "how long," or verbs associated with living must be present to convey the concept of surviving for a quantity of time; in other words, in the absence of words typically used to talk about time, discussion of time is not likely to be present. The type of analysis we performed—a quantitative analysis with qualitative examples presented—was selected because these websites have received little consideration. This type of computer-assisted quantitative analysis with qualitative examples is often a precursor to additional fine-grained qualitative analysis used when the

Table 1. Words Associated With Treatment Modalities for Kidney Failure

Treatment	Organization A		Organization B	
	N	Incidence of Word per 1,000 Words	n	Incidence of Word per 1,000 Words
Dialysis (all types)	346	4.40	1,490	10.05
Hemodialysis	50	0.64	248	1.67
Peritoneal dialysis	33	0.42	117	0.79
Kidney transplantation	90	1.14	255	1.72
CKM-related words	0	0.00	35	0.24

Abbreviation: CKM, conservative kidney management.

text is very extensive³⁰; the general goal consistent with the methodology employed is to provide a catalog of the types of information that are included and not included on the website.

RESULTS

We focused on the objective presence or absence of certain words that are necessary for ideas relevant to shared decision making—words related to treatment modalities, life expectancies, and QoL. Examples of these words creating relevant meanings are shown in [Table S2](#).

Treatment Modalities

As outlined in [Table 1](#), the 2 websites primarily emphasized dialysis as a treatment method. Organization A mentioned transplantation 90 times; Organization B, 255 times; meaning that both organizations mention dialysis multiple folds more than transplantation; organization A mentioned dialysis to transplantation at a rate of 173:45, and organization B mentioned it at a rate of 298:51. Similarly, organization A did not appear to employ keywords that could be associated with CKM approaches ([Table 1](#)), whereas organization B did employ relevant CKM keywords at a ratio of 1 CKM mention to slightly more than 34 dialysis mentions.

Life Expectancy

Organization A did not appear to feature any statements related to encouraging discussion of prognosis, while organization B had 8 statements using the word prognosis ([Table 2](#)). Of the 8 mentions of prognosis, organization B presented primarily optimistic pictures of life expectancy, stating that there are treatment options “that can help people live well for decades” and “some people live for decades with dialysis treatment.” An additional 1 of the 8 organization B’s prognostic statements asserted that “people who choose supportive care without dialysis may live for months or sometimes a year or more.”

Mentions of mortality seldomly occurred in the websites ([Table 3](#)). Of these few instances, most appeared to attribute death to nondialysis causes or reference death in medicolegal context. Significantly, none of organization A’s identified mortality instances attributed death to complications from dialysis, but rather framed death as

something that happens because of kidney disease itself, lack of transplant, comorbidities, or drug side effects. Similarly, organization B did not attribute death to dialysis complications, but only suggested that lack of dialysis could cause death: “...without dialysis or a transplant, a person with ESRD will eventually die a natural death.”

Symptoms and Quality of Life

Both organizations A and B mentioned symptoms common to kidney failure and dialysis ([Table 4](#)). The relative frequencies of mentions of side effects on the organization A and B websites were similar; however, the stated cause of these side effects varied. In our results, organization A did not attribute any of the possible symptoms—nausea, cramping, itching, headaches, hypotension—to dialysis itself ([Table 4](#)), but rather attributed these side effects to causes such as kidney failure or lack of dialysis, stating, for instance, that “most people report feeling much better once they begin dialysis” and that kidney disease can cause “swelling in the ankles and legs, foamy or bloody urine, fatigue, poor appetite, nausea [and] itching all over.” Notably, in our results, organization B did suggest that dialysis itself can cause symptoms, reminding dialysis patients “call your nurse anytime you experience any new [dialysis] side effects...[such as] nausea or abdominal cramps...talk to your home nurse if you are feeling uncomfortable.”

Wanting to explore meanings related to social and emotional well-being, as seen in [Table 5](#), we searched for sex, work, and travel; we then manually identified instances of these words that related to intimacy, employment, and transportation ([Table S1](#)). Organization A did not employ the word “sex,” whereas organization B discussed sex 17 times, suggesting that “sex and dialysis can

Table 2. Scarcity of Words Referencing Kidney Failure Life Expectancy

Treatment	Organization A	Organization B
Instances of month(s)	0	1
Instances of year(s)	0	1
Instances of survive, survival	0	0
Instances of how long	0	1
Instances of time	0	1
Instances of decade(s)	0	4

Table 3. Words Pertaining to Survival—Death, Die, Pass Away, Life Expectancy

Treatment	Organization A		Organization B	
	N	Incidence of Word per 1,000 Words	n	Incidence of Word per 1,000 Words
Instances of the word(s)	20	0.25	11	0.07
Attributed to kidney disease	2	0.03	5	0.03
Attributed to (possible) comorbidities	11	0.14	2	0.01
Discussing death with children	3	0.04	0	0.00
Pediatric congenital disease	3	0.04	0	0.00
Medicolegal or privacy	0	0.00	4	0.03
Lack of active treatment	1	0.01	0	0.00

go together” and “if you want to have more sex—or better sex—than what you are having, talk to your doctor, nurse or social worker about that, too.” Both websites provided primarily sunny projections about dialysis patients’ abilities to continue working and traveling. For instance, organization B tells patients to expect to “keep the social, school, or work life you love.” Organization A’s 22 mentions of travel primarily pertain to logistical matters such as “it is best to make travel arrangements early in advance, at least 2 months ahead of your travel, if possible, even earlier for popular destinations such as Florida and Las Vegas or at heavy travel times such as the holidays.” Organization B had 182 mentions of travel and was similarly primarily logically oriented such as “please plan 2 weeks ahead for domestic travel and 4 weeks in advance for international travel.”

DISCUSSION

In this study, we observed that the 2 largest US dialysis organizations’ websites seemed to focus primarily on dialysis as a kidney failure treatment option, and information essential to informed kidney replacement therapy

decision making may have been missing from the organizations’ materials. We noted that CKM was either not present in these materials (organization A) or present at a rate lower than dialysis (organization B). Both sites mention transplantation, albeit at a rate at least several times lower than dialysis. We also highlighted that the educational materials largely did not encourage patient–provider discussions of life expectancy and presented QoL on dialysis optimistically.

Our first main finding is that the number of instances dialysis was mentioned was many-fold higher than other treatment modalities, ie, transplantation and CKM. Significantly, one of the websites, organization A, did not appear to present CKM as a potential option. The relatively fewer mentions of transplantation and CKM may have multiple overlapping causes. It is possible that the dialysis organization websites may be best understood or intended as marketing and not patient education, though website texts claim to provide “education.” Even if the website material is classified as a direct-to-consumer marketing strategy, economic theory suggests that organizations invest in marketing only if such marketing impacts patient behaviors, and ultimately, the cost of the marketing is

Table 4. Words Describing Dialysis or Kidney Failure Symptoms and Attribution of These Symptoms

Treatment	Organization A		Organization B	
	n	Incidence of Word per 1,000 Words	n	Incidence of Word per 1,000 Words
Instances of the symptom word(s)	44	0.52	87	0.57
Types of symptoms				
Nausea, nauseous, vomit ^a	22	0.28	40	0.27
Cramp ^a	0	0.00	15	0.10
Itch ^a	13	0.17	14	0.09
Headache ^a	5	0.06	15	0.10
Attribution of symptoms				
Low blood pressure, hypotension	4	0.05	3	0.02
CKD	24	0.30	17	0.11
Dialysis side effects	0	0.00	12	0.08
Non-CKD illnesses	15	0.19	58	0.39
Medication side effects	5	0.06	0	0.00

Abbreviation: CKD, chronic kidney disease.

^aAll lemmas (forms) of these words were searched; in this case, “vomit,” “vomiting,” “vomit,” and “vomited” were all searched.

Table 5. Words Describing Social, Physical, and Emotional Well-being With Kidney Failure

Treatment	Organization A		Organization B	
	N	Incidence of Word per 1,000 Words	n	Incidence of Word per 1,000 Words
Instances of all sex, work, and travel	123	1.56	262	1.77
Sex (related to relationships, not solely gender)	0	0.00	19	0.13
Work (related to employment)	101	1.28	61	0.41
Travel (related to human movement)	22	0.28	182	1.23

offset by a gain in profits.^{34,35} It should also be noted that both organizations A and B do provide patient education classes; these organizations do engage in education, and how patients would interpret organization websites—as marketing or as education—is not known. Moreover, concerns have been raised about the business of dialysis; financial concerns may partially dictate treatment discussions.³⁶ For example, in one study, one of the cited barriers to more CKM discussions was the financial incentives of dialysis for institutions.³⁷ It is also possible that a profitability bias may not be solely responsible for a focus of dialysis as the main treatment option.³⁸ For instance, in a review of the content of 13 kidney failure patient decision aids by Davis and Davison,²⁶ the authors concluded that there is a lack of aids that present CKM as a potential choice over dialysis. The medical culture in general has an inclination toward life prolongation irrespective of its quality,³⁹ and options such as CKM are equated to “no treatment” or “giving up.”³⁷ Many physicians wish to do something for their patients, and dialysis is a tool that aligns well with this style of practice.³⁹ Nevertheless, efforts are being made to develop more patient decision aids that discuss CKM.^{40,41}

Our second finding was that the websites provided little information on the importance of discussing life expectancy on dialysis while making kidney replacement therapy decisions, information that has been deemed critical to informed decision making.¹³ Notably, one of the websites did not appear to use any words related to life expectancy on dialysis. Discussion of prognosis should be done with a supportive clinician with psychosocial and spiritual care on offer⁴²; so, we do not suggest that a decision aid should provide life expectancy prognoses. However, understanding how long one may live is an important part of ethical, informed decision making¹³; encouraging patients to raise the issue with their clinician of how much or even whether dialysis may prolong their lives may be essential to prevent dialysis decisional regret.⁴³ This relative lack of discussion of prognoses appears to be well aligned with findings of other studies that prognostic discussions between patients and nephrologists occur very seldomly.^{16,44} For instance, in one study, 60% of nephrologists stated that they would decline to give life expectancy projections even if asked directly by their patients.⁴⁵ Given this lack of prognostic conversations, it may not be surprising that patients often seem to lack understanding of their

prognoses.⁴⁶ In a study of 996 patients on dialysis, only 11.2% of patients estimated their life expectancies at 5 years or less⁴⁷ despite the fact that in the United States, 54.5% of older patients on dialysis will die within a year of dialysis initiation.⁴⁸

Finally, our analysis found that the websites seemed to portray QoL on dialysis positively; QoL words—“work,” “sex,” and “travel”—occurred many multiples more than side effects throughout both websites. Even a potentially well-intended emphasis on positive QoL on dialysis may cause patients to construct misunderstandings. QoL is frequently a key concern of patients when making treatment decisions.⁴⁹ In fact, reported QoL on dialysis is rather poor; dialysis, particularly in the frail elderly, is often associated with a substantive symptom burden, high unemployment, and frequent sexual dysfunction.^{50,51} Moreover, dialysis in the elderly is often associated with a steep decline in functional status and a high caregiver burden.⁹ Of course, in general, there is a need to maintain hope in prognostic and QoL discussions and related materials, but the limited body of research on hope suggests hope, often defined as belief in the abilities to attain future goals, can still occur in the face of serious or terminal medical conditions.⁵² Indeed, maintaining hope and truth telling are not mutually incompatible; in fact, because hope needs to be tied to what is attainable, misconstrued optimism “becomes detrimental if not tragic as the patient’s health declines and decisions about end-of-life care are made.”⁵³ Yet, it should be acknowledged that talking about prognosis can be difficult for physicians, and so, support for physicians in sharing prognostic information with patients (to the extent each patient wants it) is much needed.⁵⁴

In discussing the implications of our study, we emphasize that dialysis decision making is a complex act. For instance, decision making is impacted by patients’ past experiences and perceptions of risks and benefits.⁵⁵ Additionally, disparities in access, resources, misconstrued understandings, power differentials, and literacies may inequitably cumulatively shape patients’ abilities to understand information, engage in meaningful clinician discussions, and, ultimately, choose their courses of treatment.^{46,56} Currently, a patient contemplating dialysis decisions may not be fully aware if the purpose of these websites is marketing or education. The 2 organizations’ websites do disclose that they are for-profit, but to what

extent the patients find, understand, and act upon these disclosures is unknown. We would also like to point out that patient education is not the sole responsibility of any organization nor should patients solely be educated via decision aids or materials^{57,58}; physicians have an ethical responsibility to engage in difficult discussions about treatment options, prognoses, and QoL with patients.¹⁴ However, these prognostics discussions about life expectancy and QoL occur all too seldom; patients often report a lack of opportunity to engage in prognostic discussions with their provider.⁵⁹ The digital information landscape we have presented makes such discussions all the more needed. Training for nephrologists, who often have received very little training in communication, is needed.¹⁸ Moreover, other sources of information—printed information, internet information, education sessions, visits to dialysis units, acquaintance of someone on dialysis, and family members—may impact patient decision making⁶⁰ and merit consideration. Within this nested set of effects, patient misunderstandings do arise, and in the course of prognostic discussions, clinicians should try to undo misunderstandings.⁶¹ Studies across multiple contexts have shown well-designed material can help patients make higher quality kidney replacement therapy treatment decisions⁶²; however, little is known on the best way to aid patients in untangling potentially misconstrued health beliefs arising from educational websites of dialysis organizations which may also have a marketing component.⁶³ This is important given that surrogate information seekers already frequently use the internet,⁶⁴ and internet use is increasing among older adults.⁶⁵ Additionally, the physical and internet footprints of the major dialysis organizations' educational materials are likely to grow because chains are rapidly acquiring dialysis facilities.⁶⁶ Future studies exploring the impact of dialysis educators employed by dialysis organizations and physicians' financial partnership with dialysis organizations on informed decision making and patients' choice of transplantation and CKM are needed.^{67,68}

Our study has strengths and limitations. This study offers a replicable methodology for defining what content is and is not present in large bodies of text, such as the websites we have analyzed; such an approach offers more objectivity than a qualitative analysis may. The limitations of this study are that the study only examined parts of the websites aimed at patients (labeled as “education” or “for patients” and similar). The analysis presumed that certain words must be present for expression of certain concepts. While most concepts in our article link to specific vocabulary, not all can fully be captured by a limited vocabulary set. For instance, life expectancy and symptoms lend themselves well to our approach, whereas QoL information is more nebulous; thus, we sampled QoL information rather than captured all of it. Another limitation is that our analysis, due to scope, did not consider information present in video format or presented during possible in-person sessions. Finally, as our aim was to start studying

a literature gap—to analyze organization sites—we focused on a primarily quantitative analysis with limited qualitative examples; our goal in presenting frequencies was to show the presence or absence of key concepts. Future qualitative analyses of these websites or comparative studies with nonprofit educational websites are needed.

In conclusion, the websites emphasized dialysis as a treatment modality and provided less information about alternatives such as transplantation and CKM approaches; one of the websites did not appear to mention conservative approaches at all. Moreover, the websites seemed to link dialysis with positive QoL and provided comparably less information about dialysis symptoms and mortality. More research into how dialysis provider materials may be coloring patient decision making, as well as an ethical framework for how organizations should educate patients, are needed.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1: Concepts Important to Patient Decision-Making and Search Strategies Employed.

Table S2: Concepts Important to Patient Decision Making and Examples (If Any) Found.

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