## Factors Influencing Crowdfunding Donations for Patients with Dementia

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## Background

* With about 5.7 million people living with dementia in the United States, the cost of dementia care keeps rising
* A 2015 cost analysis study estimated the total lifetime cost of care for a person with dementia to be $\$ 321,780$; this was twice the amount for those without dementia ${ }^{2}$
* People have resorted to medical crowdfunding to fund dementia care ${ }^{3}$
*. What remains unknown are success factors of online crowdfunding campaigns for patients living with Dementia in the United States.


## Study Aim

To identify factors associated with successful, online, crowdfunded campaigns for patients living with dementia in the United States

## Methods

* A cross-sectional study of a random sample of publicly available crowdfunding pages was conducted for posts related to dementia
* The largest crowdfunding page as at the time of this study was utilized (GoFundMe ${ }^{\circledR}$ )
* Python v3.7.3 was utilized to conduct an initial web search of all campaigns including the term dementia' on September 12, 2021
- The data was formatted into a commaseparated value file
* Four independent reviewers were assigned to manually read each page to assess for eligibility based on four criteria
* Campaigns were included if they were focused on patient or caregiver of patient with dementia, an active campaign, located in the U.S, and posted in the English language
* Some of the data extracted are included in the table below.
* Pearson's chi-square test and student's test was utilized respectively to test for Statistical significance set at $\mathrm{p}<0.05$ (two-tailed)
* Data analysis was accomplished using SAS v9.4 (SAS institute, Cary, NC).


## Principal Findings

* A total of 5,899 campaigns mentioned the word 'dementia' of which a convenience sample of 2,248 were assessed manually for inclusion. 789 campaigns were included for analysis
* The upper quartile (Q3) of the ratio between donation received and donation goal was $66.7 \%$ this was used to split the results into high and low donation categories
* Average donation received by high donation category and S.E was $\$ 8610 \pm 688$ while low donation category was $\$ 2550 \pm 187$
* Patients in the racial minority were less likely to have a medical crowdfunding page and donations
* Factors associated with successful crowdfunding include longer post duration, more donors, more post sharing, more post updates, increased comments, and patients being in the racial majority
Table: Descriptive Statistics of Patients Who Sought Medical Crowdfunding for Dementia Care

| Parameters | Sub-parameters | Total Population $\mathrm{n}=789$ | High Donation $\mathrm{n}=198$ | Low Donation $\mathrm{n}=591$ | P |
| :---: | :---: | :---: | :---: | :---: | :---: |
| Post Duration (days) Mean(SE) |  | 709 (27) | 938 (53) | 632 (31) | <. 000 |
| Patient Pronoun $n(\%)$ | He/His | 338 (42.84\%) | 95 (47.98\%) | 243 (41.12\%) | 0.1191 |
|  | She/Her | 446 (56.53\%) | 103 (52.02\%) | 343 (58.04\%) |  |
|  | Other/None | (0.63\%) | o (0\%) | 5 (0.85\%) |  |
| Patient BIPOC $n(\%)$ | Likely Yes | 174 (22.05\%) | 31 (15.66\%) | 143 (24.2\%) | 0.0121 |
|  | Likely No | 615 (77.95\%) | 167 (84.34\%) | 448 (75.8\%) |  |
| Donation Received (\$) Mean(SE) |  | 4071 (241) | 8610 (688) | 2550 (187) | <. 0001 |
| Donors Mean(SE) |  | 22 (2) | 75 (5) | 24 (2) | <. 0001 |
| Post shares Mean(SE) |  | 164 (12) | 280 (36) | 125 (10) | <. 0001 |
| Post updates Mean(SE) |  | 2 (0.18) | 3.13 (0.53) | 1.62 (0.15) | 0.0003 |
| Word count Mean(SE) |  | 338 (10) | 374 (22) | 327 (13) | 0.0576 |
| Comments Mean(SE) |  | 6.7 (0.45) | 12.66 (1.24) | 4.7 (0.42) | 0001 |
| Comorbidities $n(\%)$ | None | 245 (31.05\%) | 55 (27.78\%) | 190 (32.15\%) | 0.25 |
|  | $\geq 1$ | 544 (68.95\%) | 143 (72.22\%) | 401 (67.85\%) |  |
| Cost beyond patient $n(\%)$ | Yes | 335 (42.46\%) | 78 (39.39\%) | 257 (43.49\%) | 0.3134 |
|  | No | 454 (57.54\%) | 120 (60.61\%) | 334 (56.51\%) |  |
| Costs $n(\%)$ | Medical | 156 (19.77\%) | 46 (23.23\%) | 110 (18.61\%) | 0.3606 |
|  | Non-Medical | 373 (47.28\%) | 89 (44.95\%) | 284 (48.05\%) |  |
|  | Both | 239 (30.29\%) | 60 (30.3\%) | 179 (30.29\%) |  |
|  | None | 21 (2.66\%) | 3 (1.52\%) | 18 (3.05\%) |  |
| Category $n(\%)$ | Alive | 568 (23.7\%) | 146 (73.74\%) | 422 (71.4\%) | 0.5269 |
|  | Dead | 221 (28.01\%) | 52 (26.26\%) | 169 (28.6\%) |  |
| Relationship $n(\%)$ | Family | 602 (76.3\%) | 142 (71.72\%) | 460 (77.83\%) | 0.0798 |
|  |  | 187 (23.7\%) | 56 (28.28\%) | 131 (22.17\%) |  |

Figure: Pyramid Plot Showing Relationship Between Donation Use Category vs Target Goal


## Conclusions

* Our study highlights the potential hardship associated with dementia care in the U.S
* Individuals have resorted to medical crowdfunding campaigns to finance the cost of treating/managing dementia
* Successful campaigns share characteristics hat can increase publicity and motivate donors to spend their money
* Increased donation was observed for posts directly related to medical, illness \& healing
* Racial disparities exist in medical crowdfunding


## Policy/Practice Implications

* Strategies should be implemented to offset expenses for caregivers so they do not have to resort to using GoFundMe to cover additiona costs related to caregiving
* Patients with dementia seeking help via medical crowdfunding platforms may be able to adopt some aspects of our findings to increase the success of their campaigns
* Data from crowdfunding sites can provide a rich source of information about patient and caregiver needs for researchers, patient advocates and policy makers


## References

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