"I cannot care for her entirely on my own:" Medical crowdfunding requests for persons with dementia and their families

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Background: Dementia imposes substantial financial strains on US society.[1-3] On an individual level, many persons with dementia (PWD) and their families struggle to afford the care they need. Medical crowdfunding campaigns for PWD or their families are a novel data source that can provide rich insight into the nature of costs to individuals related to dementia, illustrate the impact these costs have on the experience of illness and caregiving, and identify potential areas of focus for future policy interventions.

Objective: To characterize the full range of types of costs for which PWD and their families seek support via the crowdfunding platform GoFundMe.

Methods: We collected a random sample of 89,645 crowdfunding campaigns posted on GoFundMe in the United States from 2010 to August 2020. We identified 566 campaigns that contained the following word fragments, accounting for common misspellings: dement*, alzh*, alzeimer*, or "alziemer*. Using the identified campaigns, we conducted a summative content analysis to inductively evaluate the nature of financial needs described in the campaigns. Two coders (CCF, AHM) read 120 random campaigns and recorded eligibility, dementia type, campaign writer's relationship to the PWD, type of financial request, and financial circumstances (e.g., insurance status, job loss). After confirming interrater reliability was high (Cohen's kappa >0.6 for all categories), the remaining 446 campaigns were single-coded.

Results: After excluding 226 ineligible campaigns, 240 were included in our analysis. The most common specified type of dementia was Alzheimer's disease (n=95; 40%), with smaller proportions of campaigns naming vascular (n=16; 7%), frontotemporal (n=14; 6%), Parkinson's (n=9; 4%), and Lewy Body (n=8; 3%) dementias. The type of dementia was unspecified in 103 campaigns (43%). While most campaigns were written by family members (n=137; 57%), many were written by friends, neighbors, or coworkers (n=51; 21%). Only two campaigns (0.8%) were written by PWD themselves. The remainder did not specify the relationship between the campaigner and PWD (n=49; 20%). In 16 (7%) of campaigns, the PWD was deceased.

Campaigns requested money for a wide range of costs for PWD, their caregiver(s), or both (Figure). Most campaigns requested money for the PWD (n=208; 87%). Almost half of these requested funds (n=114; 48%) were to ***support long-term care*** in a facility (n=56) or at home (n=58). In-home long-term care expenses included home health personnel and home accessibility modifications. Many campaigns also requested funds to pay for the PWD's ***medical care*** (n=100; 42%). Most of these expenses (n=90) were not related to dementia, but rather other to other medical problems such as cancer or need for surgery. Other requested funds for PWD included ***basic living expenses*** such as home maintenance, food, and housing. Over a third of campaigns (n=90; 38%) requested ***money for family members***. The plurality of requested funds were for the family member's medical care (n=37) and housing (n=23). Other requested funds for family members included food, home maintenance, and travel related to caregiving responsibilities. A number of campaigns provided information on the financial circumstances surrounding the fundraising campaign, including job loss of the PWD (n=33; 14%) and caregiver (n=40; 17%). Other PWD and family costs, as well as illustrative quotes for all cost categories, appear in Tables 1 and 2.

Conclusions: In this descriptive study of GoFundMe campaigns related to dementia, the most common financial requests were to cover the costs of long-term care and non-dementia-related medical care for the PWD, consistent with prior formal cost-of-illness studies. Our findings demonstrate that financial strain related to dementia extends far beyond the PWD themselves: many campaigns were written by non-family members, family costs represented a substantial proportion of costs for which money was being requested, and many family members had lost jobs because of caring for a PWD. The findings reinforce the need for further research on dementia's impact on social networks of PWD (extending beyond primary caregivers) and the need for policy solutions to individual financial strain associated with dementia.

Figure: Overlap of costs of person with dementia and family costs (N=240)

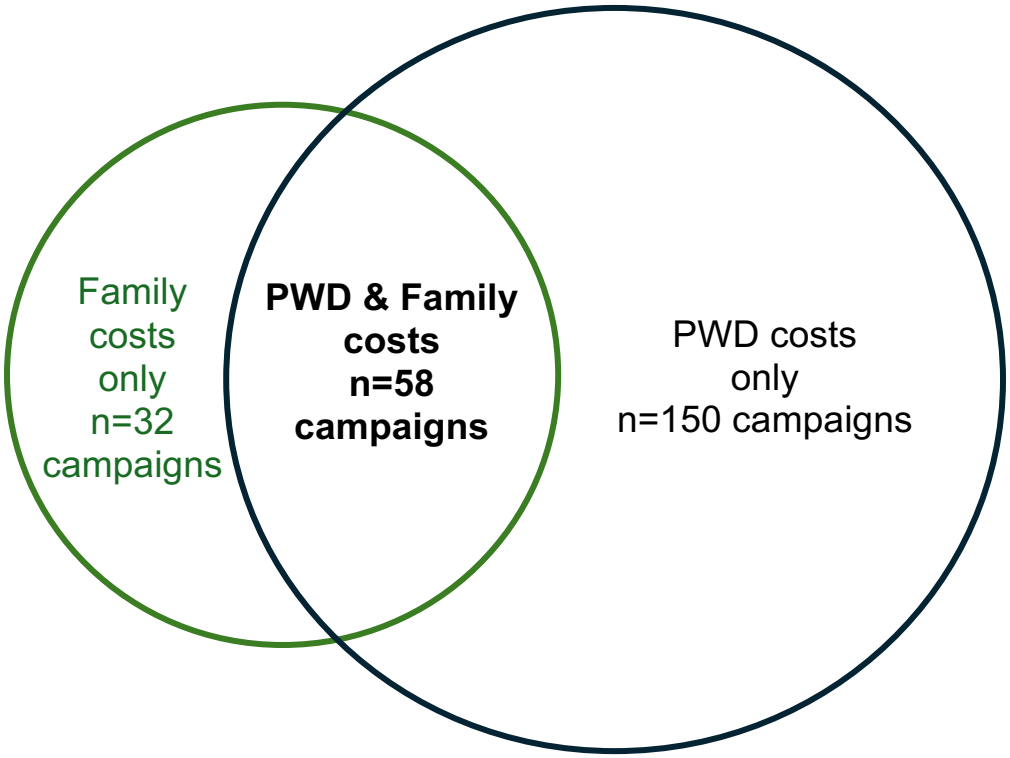


Table 1: Gofundme fundraising requests for persons with dementia (n=208 of 240 eligible campaigns)

COST	n	% of all eligible campaigns	Representative quotations
A. Long-term care			
1. Facility costs	56	23	*"As much as we have fought this as a family, we now have to move Mama [XXX] to an assisted living facility"*
2. Home or community-based care			
a. Home health personnel	48	20	*"Sadly I cannot care for her entirely on my own because she needs to be monitored through the night and I cannot function at my job on no sleep. The only viable option is to provide her with a night time home care attendant."*
b. Home accessibility modifications	10	4	*"There will need to be a ramp installed. The bathroom needs a raised toilet and the tub must be removed to add a shower. There is a large opening at the stairwell that must be walled off and a door installed. Right now if he were to stumble as he walked past it, he would fall down the stairs."*
B. Medical care	100	42	*"Kenny and his family now need our help in order to pay for Scans, medicine, and Dr. bills."*
C. Other care-related costs			
1. Durable medical equipment	10	4	*"a cane or walker"*
2. Personal care items	3	1	*"general items needed for his day-to-day, 24-hour care such as adult diapers, bedsheets, wipes, and other costly related in-home care resources"*
3. Healthcare-related transportation	6	3	*"Ambulatory transport to the SNF is $265"* *"gas to get him back and forth to his doctor appointments"*
4. Relocation	8	3	*"He and his wife of 71 years need to get home to their family in Indiana so they can have support"* *"we desperately need financial assistance to get [XXX] settled in Richmond"*
D. Not related to care			
1. Housing	15	6	*"a mortgage"* *"a security deposit on an apartment"*
2. Food	15	6	*"We can't even afford food after paying as much as we can of the bills each month. In other words, we need an immense amount of help to even eat"*
3. Home maintenance and repairs	11	5	*"They are in need of financial assistance for the up keep of the home, to keep it a safe and comfortable environment"*
4. Transportation	8	3	*"Hopefully have enough left over to finally purchase a vehicle"*
5. Other miscellaneous or unspecified costs	40	17	*"Pops mentions every day how he wishes he had his own dog again. As much as we would like to get this process started right away, financially this is out of our reach. These therapy dogs cost anywhere from $15 to $20,000"*

Table 2: Gofundme fundraising requests for family of persons with dementia (n=90 of 240 eligible campaigns)

COST	n	% of all eligible campaigns	Representative quotations
A. Basic Living Expenses			
1. Housing	23	10	*"It's hard to even pay my mortgage now and always have in the back of my mind that one day I will be evicted out of my house."*
2. Food	15	6	*"She needs help with rent, groceries, essentials. Anything to get her by."*
3. Home maintenance and repairs	5	2	*"[XXX]'s home needs repairs but with all of the medical bills they can't afford to make the repairs."*
4. Transportation	10	4	*"Snow tires, regular tires for their car, semi-annual auto maintenance"*
5. Unspecified daily living costs	13	5	*"cannot pay for my daily living"*
B. Travel or moving related to caregiving	6	3	*"I do not have the resources to cover the costs of airfare, rental car, pet sitting and any/everything else that is about to hit. All I know is that I have GOT to get to my mother"*
C. Medical care	37	15	*"they sold all they had but are still short for most of the expenses to allow them to get the medical treatment they both need"*
D. Miscellaneous or unspecified costs	30	13	*"Your donation will help support [XXX] as she remains [XXX]'s foundation through this anxious and difficult time."*

REFERENCES

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