A Community Organizing Approach to Identify and Address the Barriers to Healthcare for Patients with X-Linked Dystonia Parkinsonism (XDP) in Panay Island, Philippines

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Abstract

X-linked dystonia Parkinsonism (XDP) is a rare movement disorder that occurs predominantly in men with ancestry to Panay Island, Philippines. In a local clinic in Capiz, a province in Panay, low attendance rates and few new patients posed a constant problem to health providers. To assess these barriers and improve care, researchers implemented a community organizing program where hired "community advocates" oversaw a group of XDP patients in the region where they live and conducted three community surveys (n=167). The major barriers to care for the patients were identified: no money for transportation (44%), rain and weather issues (24%), patient not feeling well enough to go (16%), no companion to accompany patient (8%), patient embarrassment (5%) and other reasons (3%). Clinic attendance increased by 36% in the first month and 18% in the next month after implementation of the program. The data suggest that clinic attendance can be improved by taking a community-based approach to addressing the major barriers to health.

Introduction

- From April to September 2014, health care and medications were provided free of charge to qualifying (low-income) XDP patients at a local health center in Capiz.
- Despite the availability of free services, health providers noted low attendance rates and few new patients. Counseling of XDP patients has been difficult and multiple barriers to care have been hypothesized by past researchers and current providers:
  1. Financial insecurity
  2. Social isolation and stigma
  3. Lack of understanding and awareness of the disease
  4. Lack of continuity of care[1]

Methods

- Between September to December 2014, patients with XDP were identified by approaching people who were waiting at the free clinic and traveling door-to-door in nearby areas.
- All patients gave verbal informed consent to participate in the community organizing program and survey.
- A community organizing program was implemented where hired "community advocates" (CAs) oversaw a group of patients with XDP in their vicinity.
- A survey, administered by interview, was conducted (n=113) by community advocates from September to November 2014 to collect demographic and socioeconomic data.

Methods: Community Advocate Program

Community Advocate (CA) Role: Local representatives who maintain relationships between health care staff and patients. CAs visited patients and families in their homes to disseminate educational information, facilitate patient attendance at clinics through transportation plans, and help recruit and identify new patients.

Interventions implemented:

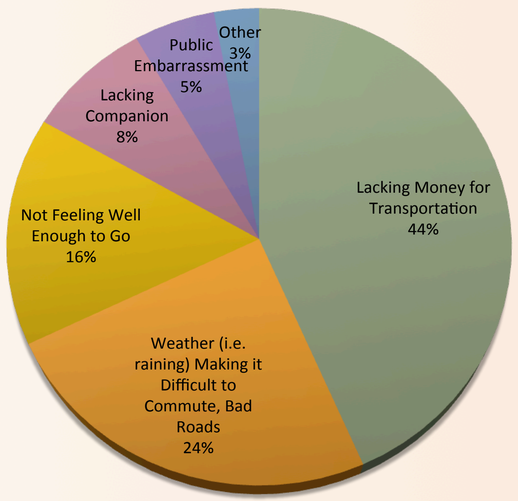
1. Paying transportation costs
2. Ensuring adequate notification of clinic date and time
3. CA training and information dissemination to all patients (i.e. basic nutrition, care of hypertension and diabetes, and government social resources)

Results

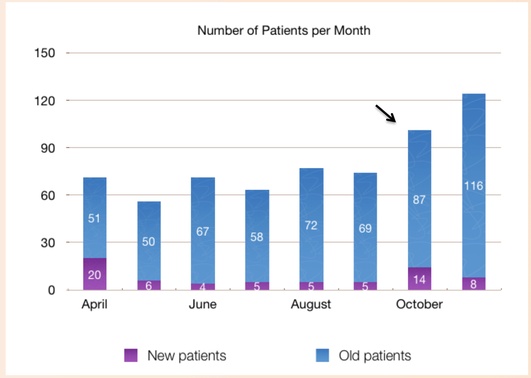
Baseline Demographic Profile	(n)
Age (mean)	51.7 (112)
Highest Educational Attainment	(113)
Completed grade school or grade school level	36% (40)
High School completion or high school level	26% (29)
College/vocational School or college level	38% (44)
Employment	(113)
Types of employment patient currently works or worked in the past*:	
Physical labor (i.e. farming)	73% (83)
Desk/office jobs (i.e. store keeper, manager)	7% (8)
Military work, security, or police workforce	6% (7)
Seaman	8% (9)
Technical jobs (i.e. mechanic, electrician)	7% (8)
Teacher	5% (6)
Engineering, computer science	3% (3)
Number of children (mean)	3.3

*Multiple response question

Reasons for Not Seeking Medical Care (n=113)

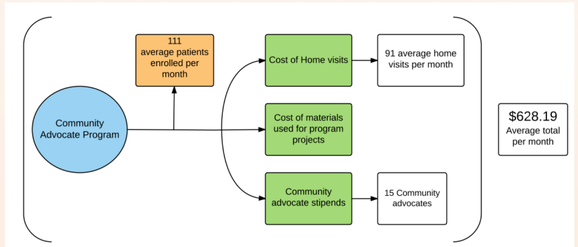


Increased clinic attendance due to interventions: When the community advocate program was implemented in October 2014, the number of patients rose by 36% in the first month and 19% in the second month, compared to the previous months.



Cost analysis of transportation and program expenses

Mean Amount Spent on Transportation before Community Advocate Program	Mean Amount Spent on Transportation during Community Advocate Program	Percent reduction in transportation costs per patient
$5.81	$3.78	35%



Conclusions

- Providing free transportation to clinics that is convenient to the patients and their families can be a cost-effective way of ensuring attendance to clinics. Free transportation addresses other barriers to attending the clinic: lacking a companion, feeling embarrassed in public, and forgetting or not knowing when the clinic is.
- The Community Advocate model can provide a way to ensure that medical care and social services provided by organizations in resource-limited settings are culturally-sensitive, effective, and practical to the population being served. Ideas for change and solutions were primarily generated and implemented by community members, such as patients and family members.
- The job of a community advocate provides a source of income for affected patients with XDP, which patients and families can use to improve their health and social environment.

References

Lee LV, Corazon R, Teleg R *et. al.* The unique phenomonology of sex-linked dystonia parkinsonism (XDP, DYT3, "Lubag"). International Journal of Neuroscience 2011; 121, 3-11.

Acknowledgments

This research project was funded by the Sunshine Foundation. We have the deepest appreciation for all of the people in Panay affected by XDP who participated in this research.