



Health Literacy Regarding Epilepsy Surgery in the Community and the Impact of Knowledge Translation

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Abstract

Introduction: Although surgical management of drug-resistant epilepsy is significantly underutilized, a representative population of potential surgical candidates has not been used to assess patient desire as a potential barrier. This study recruits patients from a community organization with a high disease burden to evaluate the impact of “basic knowledge translation (KT)” on interest in surgery. Initial data from an ongoing large-scale multilanguage study across many Canadian organizations utilizing a video-based “comprehensive KT” initiative is presented as well.

Methods: Online surveys were administered to potential respondents in series, with those from the first organization of contact receiving a “basic KT” initiative and immediate reassessment of interest. Clients from other organizations are currently being randomized to “comprehensive KT” or no intervention and interest reassessment is delayed in time. Questions assess demographics, epilepsy burden, epilepsy surgery knowledge, and pre- and post-intervention interest.

Results: Of 48 “basic KT” recipients, 67% had failed over two medications and 78% experienced seizures within the last year. The rate of disinterest improved following information about surgical benefits (26 to 16%, $p=0.0001$) but this was no longer significant after subsequently receiving surgical risk information (26% to 20%). Overall, clients had conservative views regarding surgical benefits and overestimated opinions of the risks. Of 19 “comprehensive KT” recipients recruited to date, the intervention group had increased interest by 15% following intervention while the control group had no significant change (3% decrease in interest).

Conclusions: A significant portion of potential epilepsy surgery candidates overestimate risks, underestimate benefits, and do not desire surgery. “Basic KT” of surgical benefits mobilized patient interest, which was lost with subsequent crude descriptions of risks. Initial data following “comprehensive KT” suggests that viewing an online visual comprehensive educational module increases interest while including sensitive discussion of risks. Together, this underlies the importance of careful patient counseling.

Introduction

– The prevalence of epilepsy is 0.5-1% and one third of these are medication resistant.

– Surgery is highly successful with 75% seizure free one year after surgery and major complications are rare.

– Surgery is very under utilized with <5% of eligible patients being treated.

– Previous estimates suggest that 30-49% of eligible patients are interested in surgery, but this data is poorly generalizable as the former asked about interest in the context of guaranted ideal outcomes and the latter utilized a cohort with a low medication

Methods

– Knowledge translation (KT) occurred in series with a "Basic" text-based survey-provided KT administered to Epilepsy Halton Peel Hamilton community epilepsy agency members.

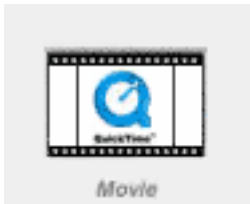
– Following this, all members from consenting epilepsy agencies across Canada were randomised to a "Comprehensive" video-based extensive KT or no intervention.

Fig 1. Basic KT

33. Studies show that 9 out of 10 of people who have brain surgery for epilepsy are satisfied with their surgery, and 8 out of 10 said that it had a significant impact on their life. If you were told by a physician that brain surgery was an option to treat your seizures would you be interesting in it? [Data sources: Dupont 2006, Chin 2006].	<input type="checkbox"/> Definitely <input type="checkbox"/> Probably <input type="checkbox"/> Undecided <input type="checkbox"/> Probably not <input type="checkbox"/> Definitely not
34. Studies show that 15 out of 20 people who have brain surgery for epilepsy are seizure-free for one year after their surgery. 14 of these people are still seizure free 10-20 years after their surgery. Many of the others, while not free of seizures, experience reductions in the number of seizures they experience. These people also experience an improved quality of life. If you were told by a physician that brain surgery was an option to treat your seizures would you be interesting in it? [Data source: Benifla 2008, Cohen-Gadol 2006].	<input type="checkbox"/> Definitely <input type="checkbox"/> Probably <input type="checkbox"/> Undecided <input type="checkbox"/> Probably not <input type="checkbox"/> Definitely not
35. Studies show that the risk of either a severe neurological complication (eg. paralysis, memory loss) or infection from epilepsy surgery are very rare (2-3%). Other complications are extremely rare. If you were told by a doctor that brain surgery was an option to treat your seizures would you be interesting in it? [Data source: Wiebe 2001].	<input type="checkbox"/> Definitely <input type="checkbox"/> Probably <input type="checkbox"/> Undecided <input type="checkbox"/> Probably not <input type="checkbox"/> Definitely not

The basic KT technique was administered within survey text. It references prominent relevant studies.

Fig 2. Comprehensive KT



The comprehensive KT describes all facets of epilepsy surgical care from initial assessment to risks/benefits of surgery to postoperatively course

Results – Basic KT

Table 1. Clinical Characteristics				
		n	%	
Gender	Male	22	46.8	
	Female	25	53.2	
Age (years)	0-17	18	38.3	
	18-25	6	12.8	
	26-40	11	23.4	
	41-65	3	6.5	
Age of first seizure (years)	0-17	34	73.9	
	18-25	5	10.9	
	26-40	4	8.7	
	>41	3	6.5	
Most recent seizure	<1 month ago	24	52.2	
	1 – 6 months ago	6	13.0	
	6 months – 1 year ago	6	13.0	
	1 – 5 years ago	8	17.4	
	>5 years ago	2	4.3	
Seizure type (in the last year)	None	4	8.5	
	Partial	22	46.8	
	Generalized	12	25.5	
	Unsure	9	19.1	
# AEDs used (cumulative)	1	8	17.8	
	2	7	15.6	
	3	8	17.8	
	≥4	22	48.9	

Table 2. Attitudes Towards Epilepsy Surgery				
	Baseline n (%)	After data on Satisfaction n (%)	After data on seizure-freedom n (%)	After data on complications n (%)
Definitely	3 (7)	5 (11)	5 (11)	3 (7)
Probably	8 (19)	15 (33)	17 (38)	16 (36)
Undecided	21 (49)	17 (38)	16 (36)	17 (38)
Probably not	7 (16)	7 (16)	6 (13)	7 (16)
Definitely not	4 (9)	1 (2)	1 (2)	2 (4)

Data on post-op satisfaction and seizure freedom rates increased interest in surgery from 26% to 49% ($p=0.0001$). Subsequent complication rate data reduced interest to 42% which is not significantly different from baseline ($p=0.285$)

Table 3. Knowledge of the Benefits of Surgery				
		Agree n (%)	Neutral n (%)	Disagree n (%)
Knowledge:	is dangerous	14 (30)	27 (59)	5 (11)
	is experimental	10 (22)	25 (54)	11 (24)
	is a last resort treatment	21 (47)	19 (42)	5 (11)
“Epilepsy surgery...”	leaves people as vegetables	5 (11)	29 (64)	11 (24)
	is less effective if delayed	4 (9)	30 (65)	12 (26)
	can effect seizure freedom	15 (33)	26 (58)	4 (9)
Benefits:	increases one’s independence	18 (39)	25 (54)	3 (6)
	increases work productivity	20 (44)	22 (49)	3 (6)
	enhances one’s social acceptance	16 (35)	26 (57)	4 (9)
“Epilepsy surgery...”	enhances one’s relationships	12 (26)	31 (67)	3 (6)
	is satisfying to most who receive it	19 (42)	25 (52)	1 (2)

Table 4. Impressions of the Risks of Surgery				
	Very likely n (%)	Somewhat likely n (%)	Somewhat unlikely n (%)	Very unlikely n (%)
Focal neurological deficits	3 (7)	30 (68)	10 (23)	1 (2)
Infection	1 (2)	27 (61)	10 (23)	6 (14)
Becoming dependent	1 (2)	23 (52)	15 (34)	5 (11)
Death	1 (2)	20 (46)	16 (36)	7 (16)

Results – Comprehensive KT

– Of 29 “comprehensive KT” recipients, 17 were randomized to video intervention and 12 to no-video control.

– Similar significant burden of epilepsy with 50% having seizures witin the past month and 70% having used =4 AEDs.

– A two week follow-up survey showed that interest in epilepsy surgery increased by 15% in the intervention group compared to a 3% decrease in interest in the control group.

Conclusions

– Patients largely underestimate the benefits of surgery and overestimate the risks.

– 25% of people with epilepsy are intertested in surgery and 50% are undecided.

– Passive written information about the benefits of surgery mobilizes an additional 25%, although interest is reduced after patients receive subsequent information about the risks.

– A comprehensive knowledge translation tool with in depth descriptions of risks/benefits increased interest by 15% based on interim results.

– Given the significant impact of counselling on patient interest in surgery, it is important for primary care physicians to undergo careful cousselling with patients with epilepsy.

Future Directions

– Continue gathering data on patients within epilesy organizations across Canada randomized to comprehensive KT versus control.

– Further work regardng tools to educate primary care physicians on potential epilepsy surgery candidate criteria or tools to empower patients to demand a certain standard of care.

References

(1) Theodore et al., Epilepsia, 2006. (2) Kwan et al., N Engl J Med, 2000. (3) Benifla et al, Epilepsy Res, 2008. (4) Falowski et al., Neurosurgery, 2012. (5) Ontario Health Advisory Committee, Health Quality Ontario Publication, 2012. (6) Prus et al., Epilepsy Behav, 2010. (7) Erba et al., Epilepsy Behav, 2012.