



Arts-based knowledge translation in aerial silk to promote epilepsy awareness

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ABSTRACT

Introduction: Arts-based knowledge translation (ABKT) strategies represent an innovative approach to disseminate results of qualitative studies, especially to tackle social issues, such as stigma and prejudice, due to knowledge gaps. Epilepsy affects 1% of the world population and brings a strong psychosocial impact to the patient, family members, and caregivers. People with epilepsy have difficulties to establish social relationships due to stigma.

Methods: In this study, we narrate the construction of an aerial and contemporary dance based on the results of a qualitative study with patients with epilepsy, their families, and health professionals, called “Dialogue with Emotions” to overcome barriers and to improve quality of life in epilepsy”. Under the ABKT classification, this study is defined as a strategy of subjective key messages, which are presented as active performances (contemporary dance and aerial acrobatics).

Results: In this sense, the choreography called “Perspective” presented elements that relate to suffering, pain, fear, social isolation, followed by mutual support, resilience, adaptation, and happiness. Through its scenic poetry and acrobatics combined with special lighting effect and soundtrack, this choreography represents the potential to overcome suffering and experience happiness if people embrace a different perspective over epilepsy.

Conclusion: This presentation conveyed perceptions on epilepsy in a way to create an experience for its audience. It represented an opportunity to stimulate reflection, discussion, and knowledge construction between members of the academy, as well as patients and caregivers. Thus, this artistic presentation was able to promote discussions about epilepsy, disseminating research results, promoting empathy and compassion.

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1. Introduction

Epilepsy is the most common chronic neurological condition in the world, with a lifetime prevalence of 7.6 per 1000 people [1] and comprises a major psychosocial burden [2]. Challenges include fear of revealing the condition, unpredictability of seizures and stigma. Stigma comes from an unmet status defined by society or by the person, which generates prejudice and unacceptance [3]. This condition directly affects behavior and quality of life, not only of the person with epilepsy (PWE), but also of their family [4]. Fear and anxieties caused by social stigma may be one of the most important factors that cause psychological distress among people with epilepsy [5].

In this context, health education strategies play an important role to break prejudice and change paradigms on epilepsy. Associations and nongovernmental organizations embraced the task of supporting people with epilepsy in the fight against prejudice. In Brazil, the non-governmental organization Assistência à Saúde de Pacientes com Epilepsia (ASPE) was created in 2002 as the official executor of the Demonstration Project on Epilepsy as part of the Global Campaign Epilepsy Out of Shadows [6]. Along with the Brazilian Institute of Neuroscience and Neurotechnology (BRAINN), based at the University of Campinas, both organizations disseminate academic knowledge about epilepsy to the community, providing educational materials, lectures and training in schools, and public events.

Diffusion and translation of research findings into evidence-based practice represents one of the major goals of research in health sciences, especially in nursing [7–9]. Nevertheless, efforts in assuming the evidence-based practice as a paradigm, methodology, and pedagogy in health professions encounter the gap between the rapid rate of knowledge production and the slower pace of evidence implementation

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in clinical practice [10–12]. This “knowledge-to-practice” gap creates a growing need to improve strategies of evidence-based dissemination and implementation. Traditional approaches as conference lectures, peer reviewed papers and book chapters are successful in presenting results to the academic audiences, but less accessible to the greater public [7].

Arts-based knowledge translation (ABKT) strategies represent an innovative approach to disseminate and communicate knowledge [13], and play an important role in tackling social issues, as stigma and prejudice. These strategies reach a broader audience, which includes patients, family, caregivers, healthcare professionals, students, managers, and policy makers [10]. The use of arts in health research is only beginning to be uncovered. For instance, applications include creating illustrations to engage the patient and family in treatment [14]; theatrical performance to develop clinical skills [15,16]; a play to transmit perceptions of human immunodeficiency virus (HIV) stigma [11]; and a dance to disseminate research results [17].

The ABKT offers alternative ways of producing research, promoting education, and changing behaviors. Applying art forms in these processes evokes emotional responses and creates different ways of representation, which enable dialog and shared storytelling [10]. Moreover, emotional experiences represent a greater value in terms of memory creation and learning. Rand [18] describes arts as “a natural and ancient way of knowing both the world and our place in it”. According to Abrahamson [19], in order to assign meaning to new artifacts, knowledge acquisition comprises a process of linkages and abstractions, establishing connections to previous experiences and memories. Cognitive learning strives for an apprehension of the whole, described by Archibald [20] as the holism of aesthetics knowing. For Archibald, this transformation relies on “acute and active perception of the object or situation” [20]. This concept has a strong link with what Dewey [21] described as an esthetic experience. In this sense, the real work of art is only concluded when performed to an audience, which is when the experience happens [14].

The potential of ABKT strategies is only beginning to be uncovered. The study called “‘Dialogue with Emotions’ to overcome barriers and to improve quality of life in epilepsy” with patients with epilepsy, their families, and health professionals provided insights into perspectives and perceptions of epilepsy. These findings presented a great potential for knowledge dissemination focusing on epilepsy awareness. In this paper, we narrate the process of analyzing results of the aforementioned qualitative study and creation of an aerial and contemporary dance to communicate these findings to a broader audience. Thus, our aim was to demonstrate through arts our research findings on emotional burden related to epilepsy.

2. Methods

This is a qualitative and descriptive study to report the construction of an ABKT project. We applied concepts of ABKT to analyze research findings and elaborate an artistic presentation, called “Perspective”. The ABKT comprises four different strategies to translate knowledge through arts, which are classified as passive or active, and precise or subjective [10]. Under the ABKT classification, this study is defined as a strategy of subjective key messages, which are presented as active performances (contemporary dance and aerial acrobatics). This method was applied in a previous project by Spagnol and colleagues [22].

The current performance was based on results of a qualitative study with patients with epilepsy, their families, and health professionals, called “‘Dialogue with Emotions’ to overcome barriers and to improve quality of life in epilepsy”. This study was approved by the local Ethics Committee. The performance was presented at the opening ceremony of the XIV National Meeting of the Brazilian Federation of Epilepsy (March 4, 2016) and at the BRAINN Congress (April 13, 2016). The first event is a national annual meeting for associations devoted to the cause of epilepsy in Brazil, hosting patients, caregivers, and

volunteers, as well as researchers devoted to voluntary activities. The second is an international annual conference that gathers researchers and students in the field of Neuroscience and Neurotechnology at the University of Campinas.

3. Results

3.1. From research findings to research synthesis

The research project “‘Dialogue with Emotions’ to overcome barriers and to improve quality of life in epilepsy” established groups sessions of 1 h per week with an average of 15 adult participants, including patients with epilepsy, family, and caregivers at the Neurology Outpatients Clinics during one year. Research findings from these group sessions were resumed in themes as per their frequency of report, and included topics as: fear, shame, and lack of control related to seizures; restriction and adaptation in reference to the process of adapting to a new condition; stories that describe verbal or indirect stigma and prejudice, leading to social isolation; lack of knowledge concerning epilepsy and its treatment; changes in routine to include safety precautions; and moments of memory deficits after seizures. These results were presented at The Patient Conference, Mansfield College, University of Oxford, on August 2016 and later published as a chapter [23]. The idea for transforming this research synthesis into a performance came from the need to innovate in disseminating knowledge and in promoting epilepsy awareness to a wider audience.

This initiative received the support from volunteers of a nongovernmental organization called ASPE and from BRAINN. Researchers and health professionals from these institutions collaborated in providing elements and ideas to develop the script for this presentation, with the art director (Bagattini, G.) specialized in aerial silk and dance performances. This multidisciplinary collaboration included nurses, psychologists, a neurologist, epilepsy researchers, and an education specialist, providing deep insights in data interpretation and strategies to create symbols, meanings, and the choreography for this presentation.

3.2. From research synthesis to script

“Perspective” depicts the construction of a dialog between two characters who seek to establish a relationship in the midst of a universe of fears and insecurities. Cris, the girl in black, is in conflict with the discovery of the diagnosis of epilepsy. Cassidy, the girl in purple, also has epilepsy and seeks to establish a bond with Cris, to support her in this new reality shared by both, out of the shadows of prejudice and stigma. Cassidy wishes to show that there is a world for both, out of the shadows and within society. The human potential of overcoming suffering in search of happiness is experienced in scenic poetry and aerial acrobatics, establishing a bond and a mutual support between these characters.

The name Cris refers to a teenager from a series of stories previously created by researchers and volunteers from ASPE and BRAINN [24], while Cassidy pays homage to a Canadian girl with epilepsy. In 2008, Cassidy Megan created the Purple Day, motivated by her own struggles with epilepsy. Cassidy’s goal is to get people to talk about epilepsy and to dispel the myths. On this day, people from all parts of the world wear purple and organize awareness to fight against prejudice.

The script was designed to convey, in each scene, perceptions from the research synthesis. The soundtrack played an important role in transmitting emotions and in involving the audience in this experience. The use of aerial silks was a metaphor for the need to break down barriers imposed by epilepsy. In aerial silks, performers, without the use of safety lines, climb the fabric and use it to maneuver difficult figures, twists, and falls.

Also, the choice of colors establishes a direct relation with the title of the World Health Organization’s project, called “Epilepsy out of Shadows”. While Cris wears black (shadows), Cassidy wears purple,

the color for epilepsy awareness campaigns. The performance is composed of six parts (see Fig. 1), without intermission, to represent the steps of a relationship between the characters, experienced by aerial acrobatics [25]. (See Fig. 2.)

3.3. From script to the audience

We had as secondary aim a qualitative assessment on the opinion of those who attended the performance. These comments include insights from the perspective of patients and of researchers, since we had two presentations. The first was during an event for patients, caregivers, and volunteers of the national epilepsy awareness movement. The second was an annual meeting of researchers at the Brazilian Institute of Neuroscience and Neurotechnology.

First, patients referred that they felt valued when realizing that their emotions and feelings had been depicted in an artistic presentation, since it allows showing others how they experience the emotional burden of epilepsy. They also related to several scenes, establishing a connection with their own experiences. For instance, the initial scene brought the memory of isolation and fear, as well as the unpredictability of seizures and the fear, which they associated with the lighting effects and the movements that alluded to seizures. They also described a sense of freedom and personal growth related to the scene in which the character, which was later hidden in the cocoon, climbs and performs a solo on the silk.

Second, researchers expressed a positive feedback referring this strategy as a good and interesting way to communicate research. These are two different perspectives over this artistic production. We cannot assess the reach and impact of these presentations, in terms of efficiency of knowledge diffusion. This variable could be



Fig. 1. The first scene represents Cris's isolation.



Fig. 2. Cassidy watches Cris in her gradual effort to find self-acceptance.

assessed in further research, since our proposal in this article is to present the method for knowledge translation into art.

4. Discussion

This project allowed a different approach in discussing and presenting results of a research. When analyzing perceptions of patients regarding epilepsy, researchers had to reflect upon strategies to convey the patient's emotions and narratives. In order to represent these emotions, GS and GB developed several rehearsals to create movements in aerial silk that could transmit, for instance, feelings of fear, anguish, shame, and isolation.

This experience guided researchers into a deep study into patient's realities, since it required performers to step into patient's shoes, imagine their feelings from each life story. This approach bears a similarity to the proposal of the Empathy Museum, from London (UK), in which visitors are invited to listen to a person's life story while wearing his/her shoes. This is also a mean to resignify the patient experience, creating new emotions and a deeper understanding of epilepsy and its burden.

In aerial expression, movements performed in two strips of silk of 5 m in height create a wide range of figures and visual effects. The silk also allows different modalities of performance. One of these is with the silk tied in several knots in its lower ending. If a performer climbs these knots and sits between the two strips of silk above the knots, it provides a shape of a cocoon, and involves the artist.

The **first scene** represents patient's struggles, fears, and social isolation (see Fig. 1). In particular, it depicts the stigma that patients have about themselves, which results in Cris's attempt to hide from others. We chose to depict an epilepsy seizure to approach one of the greatest challenges faced by patients and caregivers, due to its unpredictability. According to a study by Kılınc and Campbell [26] about the experience of living with adult-onset epilepsy, the unpredictability of seizure occurrence was one of the three central themes, along with the ripple effect; and reevaluating the future.

Also, the first scene conveys negative feelings due to social isolation and stigma. Historically, society segregates individuals in groups according to their common features. Goffman [28] explained the relationship between these groups and individuals by using two concepts: Social Identity and Personal Identity.

The First, Social Identity, can be subdivided into two aspects: Virtual Social Identity, related to expectations created from a person's attributes associated with his/her values about society, and Real Social Identity, which represents his/her actual characteristics. When characteristics of Virtual Social Identity are equal or similar to the Real Social Identity, they are positive, allowing a symbology of prestige. When negative, that is, when expectation and reality are incongruent, there is stigma [27].

The Second, Personal Identity, provides a better understanding of one's self [28]. Among people with epilepsy, this may be directly related to the likelihood of sharing or not about their condition, or of accepting help from others, as shown in the first scene. The social relationship can lead the stigmatized to a self-defense behavior avoiding contact with others. Since disclosure controls variation of stigma, not talking about it, represented by Cris's attempt to hide from Cassidy, may be a strategy to prevent possible prejudice in certain situations [29].

Jacoby and Austin [30] define two types of stigma: felt and enacted. The first refers to the shame of having epilepsy and fear of seizures, directly related to personal perceptions of epilepsy. The enacted stigma is derived from episodes of discrimination and prejudice. Because it is related to individual perception, felt stigma can cause more personal anguish and unhappiness than the latter, because it is significantly associated with intrinsic characteristics [5].

As described by Goffman [28], when society defines an individual's attributes as depreciatives, it leads the person to become increasingly "discreditable". This term, coined by Goffman, refers to a person whose characteristics may generate stigma, but these characteristics are not fully visible. Negative attitudes toward the person with epilepsy may be associated with social distancing [31].

In theater and movies, illustrations of epilepsy remain diverse and far from an accurate and stigma-free representation. For instance, playwrights in Greece, in the 6th century BC, associated epilepsy with madness and extreme violence. In the 5th century, Shakespeare depicts epilepsy as a vulnerability in Caesar's character, which leads to his assassination, and as a demonic possession in Othello's character, who's an outsider [32]. Films have also portrayed epilepsy to add unsympathetic, out-of-control, and feared characteristics, unfortunately, often related to demonic possession [33].

The **second scene** represents Cassidy showing Cris how life with epilepsy can be — with challenges (the knots), but filled with joy. This scene bears a direct correlation to storytelling and experience sharing during the group of patients with epilepsy. Life stories of other PWE may be functional for awakening other ways of seeing suffering and creating new solutions. For instance, in group psychotherapy, the PWE is exposed to complex social relationships, which are similar to his natural environment [34]. This environment helps the patients to create conditions that can awaken awareness of contingencies of reinforcement in their life history, which may lead them to emit behaviors and aversive feelings that bring them suffering [35]. Contingencies are relations of dependence between environmental events or between behavioral and environmental events [36,37]. Sharing stories of overcoming challenges can provide another perspective for the PWE that one may become aware of one's repertoires to emit potentially larger and more satisfying reinforcement contingencies. This is the effect that Cassidy has over Cris, as illustrated in scene 2.

According to the International Classification of Functioning, Disability, and Health (CIF) and the World Health Organization (WHO), the individual is classified by the biopsychosocial model, respecting the physiological, psychic, and social conditions. In this sense, people with epilepsy may present difficulties in these areas and consequently implicate in their quality of life [38]. The CIF scheme intends to show how changes in the context influence the internal and external environment may modify the behavior of an individual toward one's own activities and perceptions.

Nevertheless, measures to adapt tasks in the work environment play an important role in increasing possibilities for inclusion of patients with different types of epilepsy. Harden and colleagues [38] state that the idea of not knowing how to intervene in a seizure and not understanding particularities of epilepsy may provoke stress and restlessness for the PWE and work colleagues. In this perspective, preventive and informative measures can reduce this concern and increase safety for the PWE in the workplace [39]. In this sense, the **third scene** is a synchronized choreography, which Cris performs while sitting in a chair and later abandons her coat, which was a metaphor for her fear and shame.

Epilepsy imposes a demand for patient care in their daily activities. The caregiver often prioritizes the PWE, letting their own needs and goals be in the background. In these cases, it is necessary to restructure family dynamics, especially when the epilepsy is difficult to control [27]. As depicted in the **fourth scene**, a silk full of knots is easily untied by the strength of two persons, not by one person alone.

In the **fifth scene**, Cris performs while Cassidy watches her from the ground. This movement represents a balance between support and freedom. During the qualitative study with patients and family, we noticed that there is a need for a balance between care provided by family and caregivers and patient's freedom. Failure to achieve this balance may result into feelings of limitation and restriction, as reported by patients, as well as fear of accidents and a great burden for the caregivers, feeling constantly concerned, even when situations do not represent possible dangers. This balance is also essential to build the patient's self confidence and self-esteem.

Guilhardi [40] describes "feelings" as bodily manifestations derived from interactions between the individual, social, and verbal community (family, friends, caregivers etc.). Self-esteem, self-confidence, and responsibility are feelings that are associated with the individual's ability to feel free, loved, to have initiative, and to be creative. The "ripple effect", as reported by Kılınc et al. [27], implies in changes in daily activities, as driving, bathing, and cooking, as well as in the family dynamic, posing a direct impact in self-esteem and self-confidence. Thus, the social community of the patient (friends, caregivers, family members) must allow a safe environment for the PWE to exercise freedom and creativity.

Quantity and quality of social interaction are directly related to the quality of life of patients with epilepsy [41]. A network of social relationships allows a decrease in stress and increases self-respect and self-esteem. People with epilepsy with strong social support report lower psychological needs because of their condition and may develop a greater sense of control over their life, allowing a mechanism of well-being and control related to epilepsy. This is depicted in the **final scene**, when Cassidy and Cris perform as equals.

5. Conclusion

This presentation conveyed perceptions on epilepsy in a way to create an experience for its audience. It represented an opportunity to stimulate reflection, discussion, and knowledge construction between members of the academe, as well as patients, their family, and volunteers. Aerial silk and dance performance with lighting and music artifacts created an atmosphere to involve the audience in the perceptions of epilepsy.

This strategy enabled tackling their previous feelings and memories regarding epilepsy or of a more general experience of suffering, followed by removal of obstacles and overcoming difficulties. A general acceptance by the audience after the performance was able to promote discussion about epilepsy and alternative ways of disseminating research results.

Declarations of interest

None.

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