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ESTUDO, EXPRESSÃO E ENFRENTAMENTO DAS EMOÇÕES DE PACIENTES COM EPILEPSIA E SEUS CUIDADORES

STUDY, EXPRESSION AND COPING WITH EMOTIONS OF PATIENTS WITH EPILEPSY AND THEIR CAREGIVERS

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Tese apresentada à Faculdade de Ciências Médicas da Universidade Estadual de Campinas como parte dos requisitos exigidos para a obtenção do título de Doutora em Ciências.

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EPÍGRAFE

"O correr da vida embrulha tudo. A vida é assim: esquenta e esfria, aperta e daí afrouxa, sossega e depois desinquieta. O que ela quer da gente é coragem."

Guimarães Rosa em Grande Sertão: Veredas

RESUMO

Introdução: a epilepsia é uma doença crônica com impacto psicossocial ao paciente e a família. Os pacientes com epilepsia podem apresentar dificuldades em expressar e reconhecer suas emoções. O objetivo geral desse projeto foi estudar sobre as emoções de pacientes com epilepsia e seus cuidadores e estratégias para sua expressão e enfrentamento. Como objetivos específicos, tem-se: analisar qualitativamente as causas de sofrimento psíquicos no paciente com epilepsia e seus cuidadores por meio do grupo Dialogando com as emoções; traduzir os resultados do estudo anterior para a expressão artística, como uma maneira inovadora de difundir o conhecimento sobre a epilepsia; avaliar o efeito agudo das Mandalas das Emoções como uma possibilidade de método para reconhecer as emoções. Método e sujeitos: foram realizados três estudos: (a) uma avaliação qualitativa sobre os sentimentos e dificuldades no dia-a-dia por pacientes e familiares, por meio de uma dinâmica em grupo com pacientes e familiares no horário que antecede a consulta médica no ambulatório de epilepsia; (b) reinterpretação dos dados dessa avaliação e apresentação dos resultados por meio da expressão artística, com o fim de buscar a conscientização e de dialogar com a sociedade sobre as dificuldades enfrentadas pelos pacientes; (c) avaliação sobre os efeitos das Mandalas das Emoções por meio de um estudo randomizado caso controle com pacientes com epilepsia e cuidadores em um Ambulatório de Neurologia. Para os estudos (a) e (c), realizamos o recrutamento dos pacientes e seus cuidadores no Ambulatório de Epilepsia de Adultos. Nos estudos (a) e (c), aprovados pelo Comitê de Ética da Faculdade de Ciências Médicas da UNICAMP, os sujeitos responderam a um questionário composto por dados demográficos e percepção sobre emoções, após o preenchimento do Termo de Consentimento Livre e Esclarecido. Em (a), o compartilhamento de histórias de vida permitiu aprendizado sobre a epilepsia e novas possibilidades de estratégias de enfrentamento da doença, criando potencial para o desenvolvimento pessoal. Em (b), a apresentação comunicou percepções sobre a epilepsia de forma a criar uma experiência para seu público, disseminar resultados de pesquisa, promover empatia e compaixão. Em (c), o estudo randomizado caso controle apresentou uma diferença significativa somente na percepção de alterações após 5 minutos do início do procedimento; com maior efeito no grupo intervenção e nos cuidadores em comparação aos pacientes. Os estudos supracitados contribuíram com benefícios tanto para a comunidade que atende, ao promover o acesso a um grupo para pacientes e cuidadores e a uma prática integrativa, quanto para a construção de evidências científicas que sustentem sua aplicação.

Palavras-chave: Epilepsia; Emoções; Enfrentamento; Terapias Complementares.

ABSTRACT

Introduction: epilepsy is a chronic disease with a psychosocial impact on the patient and the family. Epilepsy patients may experience difficulties in expressing and recognizing their emotions. The general objective of this project was to study the emotions of patients with epilepsy and their caregivers and strategies for their expression and coping. Specific objetives were: to qualitatively analyze the causes of psychological distress in patients with epilepsy and their caregivers through the group "Dialogue with emotions"; (b) to translate the results of the previous study into artistic expression, as an innovative way of spreading knowledge about epilepsy; (c) to evaluate the acute effect of Mandalas of Emotions as a method for recognizing emotions. Method and subjects: three studies were developed: (a) a qualitative assessment of feelings and difficulties in the daily lives of patients and family members, through a group experience with patients and family members at a time that precedes an outpatient medical consultation; (b) reinterpretation of the data from this evaluation and presentation of the results through artistic expression, with the objective of seeking awareness and dialogue with society about difficulties faced by patients; (c) evaluation of the effects of Mandalas of the Emotions through a randomized case control study with patients with epilepsy and caregivers in the Neurology Outpatients Clinic. For studies (a) and (c), we recruited patients and their caregivers at an Adult Epilepsy Outpatient Clinic. In studies (a) and (c), approved by the Ethics Committee of the School of Medical Sciences of UNICAMP, the participants answered a questionnaire composed of demographic data and perception of emotions, after completing the Informed Consent Form. In (a), sharing life stories allowed to learn about epilepsy and new possibilities of coping with the disease, creating a potential for personal development. In (b), a presentation communicated perceptions about epilepsy in order to create an experience for its audience, disseminated research results and promoted empathy and compassion. In (c), the randomized case control study showed a greater report of significant difference only in perception of changes after 5 minutes of procedure when comparing control and intervention; with a greater effect on the intervention group and on caregivers compared to patients. The aforementioned studies contributed with benefits both to the community it serves, when promoting access to a group for patients and caregivers and an integrative practice, as well as to increase the number of clinical studies that support its application.

Keywords: Epilepsy; Emotions; Coping Behavior; Complementary Therapies.

SUMÁRIO

INTRODUÇÃO

O contexto da epilepsia: estudo das emoções

Dentre as doenças neurológicas crônicas, a epilepsia destaca-se como a mais comum em todo o mundo, com uma prevalência de 7,6 a cada 1000 pessoas[1]. A doença impõe um peso grande nas áreas psicológica, física, social e econômica, revelando dificuldades individuais, familiares, escolares e sociais, especialmente desafios como o medo de revelar a condição, imprevisibilidade de convulsões e estigma[2].

O estigma provém de um status não alcançado definido pela sociedade ou pela pessoa, o que gera preconceito[3]. Essa condição afeta diretamente o comportamento e a qualidade de vida, não apenas da pessoa com epilepsia, mas também de sua família[4]. O medo e a ansiedade causados pelo estigma social podem ser um dos fatores mais importantes que causam sofrimento psicológico entre as pessoas com epilepsia[5].

A imprevisibilidade de ocorrências convulsivas episódicas com perda de consciência impõe restrições de direção e emprego. Desafios na autonomia fazem parte de mecanismos complexos subjacentes ao estigma na epilepsia[6-9].

A qualidade de vida é diretamente influenciada pela região mundial e categoria de renda, com menor nível de renda do país associado à pior qualidade de vida, conforme descrito em uma metanálise de estudos publicados entre 2000 e 2015 por Saadi e colegas[10]. Além disso, Szemere e Jokeit[11] destacam que a qualidade e a quantidade da interação social nas relações profissionais e pessoais são os principais fatores e preditores de bem-estar, felicidade e satisfação com a vida.

A consequência do estigma varia e pode levar ao extremo de isolamento social[3,12]. De acordo com Jacoby e Austin[13] , o estigma se divide em estigma sentido ou estigma declarado. O estigma sentido refere-se à vergonha se ter a epilepsia e o medo de encontrar-se com ela, sendo relacionado com a forma que o indivíduo percebe sua condição. Já o estigma decretado está relacionado

com episódios de discriminação e preconceito propriamente ditos. Por estar relacionado com a percepção do indivíduo, o estigma sentido pode causar mais angústia pessoal e infelicidade do que o estigma decretado.

Viver com o estigma da epilepsia, sentido ou decretado, pode resultar em distúrbios da saúde mental. O estresse e a ansiedade são maiores em crianças[14] e adultos[15] com epilepsia do que em indivíduos controle. Johnson e colegas[16] estimam que a prevalência de depressão ao longo da vida em associação com epilepsia seja tão alta quanto 55%. Não é o tamanho da rede de relacionamentos sociais, mas a qualidade estabelecida que possibilita minimizar o estresse da vida do indivíduo, aumentar o respeito, melhorar a autoestima e compreender melhor os sentimentos. Assim, a quantidade e a qualidade da interação social estão diretamente relacionadas à qualidade de vida de pacientes com epilepsia[11].

Quando comparados às pessoas sem epilepsia, os pacientes com epilepsia apresentam, em especial, maior isolamento social, maior dificuldade nos relacionamentos sociais e maiores índices de desemprego[17]. Por isso, é importante que disseminar o conhecimento sobre a epilepsia, suas implicações práticas, as dificuldades psicológicas associadas para que as pessoas com epilepsia e suas famílias deixem de ser vítimas de preconceito e estigma. Antes do início de uma aula sobre epilepsia ministrada na Faculdade de Enfermagem da Unicamp, foi solicitado aos alunos que enviassem uma palavra para definir a percepção sobre epilepsia (Fig. 1).

Figura 1. Uso de software online gratuito disponível em Menti.com para resposta em tempo real.

A nuvem de palavras que se formou ilustra os sentimentos relacionados a essa doença, os quais, somados à condição clínica, constituem-se como estressores que podem comprometer o bem-estar. A resposta humana perante esse quadro pode ser insuficiente, como definida pelo diagnóstico de Enfermagem, segundo a Taxonomia II de NANDA-International Inc.[18], "Enfrentamento ineficaz", caracterizado como "padrão de avaliação inválida de estressores, com esforços cognitivos e/ou comportamentais, que falha em controlar as demandas relativas ao bem-estar", ou apresentar um potencial para melhora, conforme o diagnóstico "Disposição para enfrentamento melhorado", caracterizado como um "padrão de avaliação válida de estressores, com esforços cognitivos e/ou comportamentais, para controlar as demandas relativas ao bem-estar, que pode ser melhorado"[18]. Entre um diagnóstico e outro, existe a necessidade de reconhecer as emoções e de fortalecer o autoconhecimento. Neste contexto, torna-se essencial traçar estratégias de intervenção.

A fim de garantir os direitos e a inclusão social de pessoas com epilepsia, associações e organizações não governamentais foram criadas, desempenhando um papel essencial no apoio às pessoas com epilepsia na luta contra o preconceito, um resultado da falta de conhecimento. Perante essa dificuldade, desenvolveu-se o Grupo de Interação Social (GIS) para profissionais de saúde e pessoas em geral interessadas no tema, tendo como base terapias já existentes[19]. O GIS teve como objetivo ampliar a abrangência no manejo integral das epilepsias, visando quatro dimensões: grupos de reflexão, atividade esportiva lúdica, terapia cognitivo comportamental e Medicina Tradicional Chinesa. Para isso, o grupo foi realizado num período de quatro horas, cobrindo os seguintes temas: manejo da epilepsia (o que é epilepsia, o que são crises epilépticas, as causas e as formas de tratamento, impacto psicossocial, reinserção social) e estratégias para formação de grupos de epilepsia na comunidade.

Os resultados do desenvolvimento do GIS apontaram uma melhora em todos os itens avaliados: habilidades sociais, autoestima, resiliência e percepção de estigma na epilepsia, conforme descrito por Fernandes et al.[17]. Em decorrência da experiência, o GIS se consolidou como uma ferramenta

muito versátil e de fácil empoderamento, trazendo benefícios para a população. Durante essa prática, de suma importância, notou-se a dificuldade dos pacientes de expressar suas emoções.

Uma das autoras do trabalho, a Dra. Ling, desenvolveu o método chamado “Dialogando com as emoções”, baseado na Medicina Tradicional Chinesa (MTC) voltado para despertar a consciência da emoção e facilitar que o paciente reconheça e trabalhe essas emoções, para que comece a lidar com os conflitos internos. Esse método foi aplicado no capítulo 1 da presente tese, intitulado “Dialogue with Emotions”, publicado no livro The Patient-Doctor Dynamics, editado por Dr. Jytte Holmqvist, uma publicação advinda dos proceedings da 5ª Conferência Global chamada The Patient – Examining Realities, a qual ocorreu de 14 a 16 de setembro de 2016 na Universidade de Oxford. A aplicação do método permitiu o estudo sobre as emoções da pessoa com epilepsia e de seu cuidador.

A partir do estudo do capítulo 1, desenvolveu-se nova pesquisa para traduzir os resultados científicos em expressão artística. O capítulo 2 da presente tese descreve o processo definido pelo método Arts-Based Knowledge Translation (ABKT), por meio do qual se elaborou o espetáculo em tecido acrobático intitulado Perspectiva. Na próxima seção, descreve-se sobre o método ABKT e exemplos de experiências em sua aplicação.

A pesquisa traduzida em arte: expressão das emoções

O método ABKT configura-se como um campo em crescente desenvolvimento, em especial, na área da saúde e na enfermagem[20,21]. Como método de ensino e aprendizagem, abre-se a possibilidade de engajamento mental e corporal, com a vivência e experimentação de conceitos teóricos e resultados de estudos, tanto para seu participante, ao se colocar como artista, quanto para seu expectador.

Na área da saúde, sua aplicação acontece em estudos com uso de desenho ou performance[22,23], análise de artes visuais para educação em

enfermagem[24] e teatro para disseminar resultados de pesquisa qualitativa[25], e para a educação popular em saúde no Brasil[26].

Na enfermagem, a história da profissão se desvela no campo da arte e da ciência, como traz a frase “a arte e a ciência da Enfermagem”[27]. A arte como estratégia para reduzir a lacuna entre o conhecimento e a ação posiciona-se oportunamente perante as expectativas contemporâneas da prática baseada em evidências em prol de melhorias na qualidade e segurança do cuidado e da democratização do acesso à saúde[28,29].

Em artigo publicado na revista de História da Enfermagem, Spagnol et al [30,31] discorrem sobre o processo de criação e apresentação para a ocasião do 67º Congresso Brasileiro de Enfermagem, de 2015. Nessa oportunidade, utilizou-se a história da enfermagem como objeto de estudo, por meio do retrato do cuidado durante a guerra. O processo de criação envolveu oficinas, rodas de conversa, pesquisa bibliográfica e imagens e resultou em um espetáculo capaz de fomentar discussões sobre as relações humanas na Enfermagem e novas possibilidades do fazer em enfermagem.

No que tange a presente tese, o artigo publicado no Journal Epilepsy & Behavior descreve a experiência da aplicação do método ABKT para expressar as emoções da pessoa com epilepsia e seus cuidadores. Sob a classificação da ABKT, trata-se de uma estratégia de comunicação de mensagens-chave subjetivas, as quais são apresentadas por meio de performance ativa, na dança contemporânea e nas acrobacias aéreas em tecido. A coreografia apresenta os elementos relacionados ao sofrimento, dor, medo e isolamento social, seguido da aceitação de apoio, da resiliência e adaptação. A partir desse momento, retrata-se a felicidade, de maneira a ilustrar a reintegração à convivência e aos relacionamentos, sugerindo melhora na qualidade de vida da pessoa com epilepsia ao adotar uma nova perspectiva sobre a doença. O intuito da coreografia foi abordar as percepções sobre a epilepsia, tal como descritas no estudo qualitativo (capítulo Dialogue with Emotions” through the Eyes of Patients with Epilepsy and Caregivers, publicado no livro “The Patient-Doctor Dynamics” e parte da presente tese), como uma oportunidade para estimular reflexão, discussão e construção de conhecimento.

Importante citar outras ocasiões da aplicação de ABKT como os espetáculos “Nós”[32], “Nuances”[33] e “VIDA”[34]. Nessas ocasiões, utilizou-se a teoria das Mandalas das Emoções, método criado pela Dr. Li Hui Ling, com base na Medicina Tradicional Chinesa, para facilitar o reconhecimento e o enfrentamento das emoções. Esse método será explicado na seção “As Mandalas das Emoções”, desta tese. As apresentações supracitadas expandiram a aplicação do método das Mandalas das Emoções para a cena e o circo, como objeto disparador para o reconhecimento e criação de emoções no palco, assim como permitiu maior diversidade de experiências na aplicação da ABKT.

O espetáculo “Nós” [32], elaborado junto aos alunos do primeiro ano da graduação dos cursos de Medicina, Enfermagem, Fonoaudiologia, Farmácia e Educação Física da UNICAMP, constituiu uma oportunidade de construção artística interdisciplinar, apresentada aos calouros dos cursos supracitados para potencializar essa discussão na área da saúde (Spagnol et al, 2017). Sua narrativa aborda as emoções da criança, durante as brigas e brincadeiras (mandala verde), a agitação do adolescente perante repentinas mudanças (mandala vermelha), as preocupações da vida do profissional de saúde (mandala amarela), o sentimento de culpa e tristeza ao se cometer um erro de medicação (mandala branca) e a coragem ao acreditar em novos inícios (mandala preta).

O espetáculo foi apresentado em quatro ocasiões: em evento especial aos calouros (18/10/2018); na abertura da semana de recepção aos calouros (02/2018); no 11o Congresso Paulista de Educação Médica (CPEM) (19 a 21/04/2018) e no Congresso Científico da Faculdade de Enfermagem (08/11/2018) (FEnf, 2018). Seu relato de experiência foi apresentado no XI International Brazilian Meeting on Cognitive Science (2017).

O espetáculo “Nuances”[33], apresentado na abertura do V Encontro sobre Neurociências na Educação Inclusiva em abril de 2018, teve como proposta utilizar a linguagem artística para estimular reflexões sobre o impacto psicossocial do bullying na escola. O processo de criação baseou-se na pesquisa e discussão sobre o bullying com alunos, pesquisadores e profissionais da Enfermagem, Fisioterapia, Medicina, Educação Física e Artes.

Utilizaram-se recursos do teatro, canto, dança e acrobacias aéreas. Junto ao ABKT, foram aplicados também os conceitos das Mandalas das Emoções e seus correspondentes com relação às cores, fases da vida e emoções, derivados da Medicina Tradicional Chinesa. Nesse sentido, o espetáculo reinterpretou por meio do canto, dança e acrobacias aéreas, as diversas camadas de emoções e atitudes sob a perspectiva de uma adolescente em suas interações sociais na escola e nas mídias digitais. O resumo sobre o relato de experiência foi premiado como melhor trabalho na categoria resumo científico no 6º Encontro sobre Neurociências na Educação Inclusiva.

Por último, o espetáculo “VIDA” [34], apresentado em agosto de 2018 na abertura do programa UniversIDADE, também utilizou os conceitos das Mandalas das Emoções. Sua abordagem baseou-se em discussões a partir de pesquisas relacionadas à depressão, ao uso das mídias digitais e ao distanciamento entre jovens e idosos. A narrativa retratou as emoções, vivências e o conflito de gerações por meio da relação de um avô e sua neta em cenas permeadas por diferentes emoções – como o humor, tristeza, medo, nostalgia, esperança e harmonia. Como resultado, despertou emoções e reflexões, de forma a destacar a importância da aproximação dessas duas faixas etárias em prol do apoio mútuo e para a promoção da qualidade de vida, como propõe o programa UniversIDADE[34].

Ao utilizar o método ABKT nesses diferentes contextos – a formação do profissional de saúde, o bullying na adolescência e a relação de duas gerações (adolescente e avô), houve um aprofundamento no estudo sobre as emoções, contribuindo para maior entendimento sobre seu processo de reconhecimento, compreensão e expressão.

A próxima seção traz as principais teorias sobre as emoções, seguida de uma explicação sobre abordagem supracitada, as Mandalas das Emoções, a qual foi utilizada como o método para o estudo das emoções nesta tese.

As emoções

A emoções constituem uma resposta humana psicofisiológica decorrente da percepção consciente ou inconsciente das experiências de um indivíduo em

relação a si mesmo e ao seu contexto biopsicossocial, associados ao humor, à personalidade e à motivação[35]. Essa resposta envolve a cognição, a comunicação e, em especial, o armazenamento de informações e o processo de tomada de decisões[36]. Reconhecer e compreender as emoções de si mesmo e do próximo, inclusive por meio das artes e da apreciação musical, são habilidades importantes para manter o equilíbrio emocional e social.

A primeira abordagem com relação às emoções, por Charles Darwin, destacou a sua importância para a sobrevivência e reprodução dos animais e seres humanos. O autor explica, no contexto da Teoria Geral da Evolução, que emoções como o medo, ao desencadear uma resposta ao perigo iminente, e o amor, ao motivar a escolha de um companheiro, contribuem para a preservação da espécie[37].

Ao longo da história das pesquisas sobre as respostas emocionais, desenvolveram-se duas principais abordagens: a discreta e a dimensional. A primeira define um conjunto de emoções básicas biologicamente definidas, independentes de diferenças culturais ou étnicas, resultantes de processos neurais autônomos e reconhecidas pela expressão fácil e reações biológicas[38].

Esse conjunto compõe-se de seis emoções básicas: raiva, repulsa, medo, felicidade, tristeza e surpresa, às quais são acrescidas diferentes emoções por outros autores. Por exemplo, Izard et al.[39] listam dez: raiva, desprezo, desgosto, angústia, medo, culpa, interesse, alegria, vergonha e surpresa. Tomkins[40] definiu como um total de nove: raiva, interesse, desprezo, desgosto, angústia, medo, alegria, vergonha e surpresa. Por sua vez, Du e Martinez[41] adicionaram às seis emoções de Ekman[38], outras quinze, as quais resultam de combinações e cujos sinais misturam expressões faciais, aumentando a dificuldade de interpretação.

Contudo, conforme argumenta Russell[42], a expressão emocional retratada nas fotos das 6 emoções básicas de Ekman capturam apenas 15-20% da variedade de emoções sinalizadas pelo comportamento, sem retratar os graus de variação e intensidade das mesmas.

Dentro da segunda linha de pesquisa, a abordagem dimensional, pode-se citar o modelo circunflexo de afeto. Este propõe que todos os estados afetivos resultam de dois sistemas neurofisiológicos fundamentais, um relacionado à valência - um contínuo de aversão a prazer, e outro à excitação ou alerta – do menor nível de energia ao maior[42].

De acordo com o modelo circumplexo, cada emoção pode resultar de uma combinação linear de duas dimensões, com graus variáveis de valência e excitação. A alegria, por exemplo, é definida como um produto do estado emocional de forte ativação nos sistemas neurais associados à valência ou prazer positivo, junto à ativação moderada nos sistemas neurais associados à excitação[43]. Emoções específicas, portanto, surgem de padrões de ativação dentro desses dois sistemas neurofisiológicos (Figura 2).

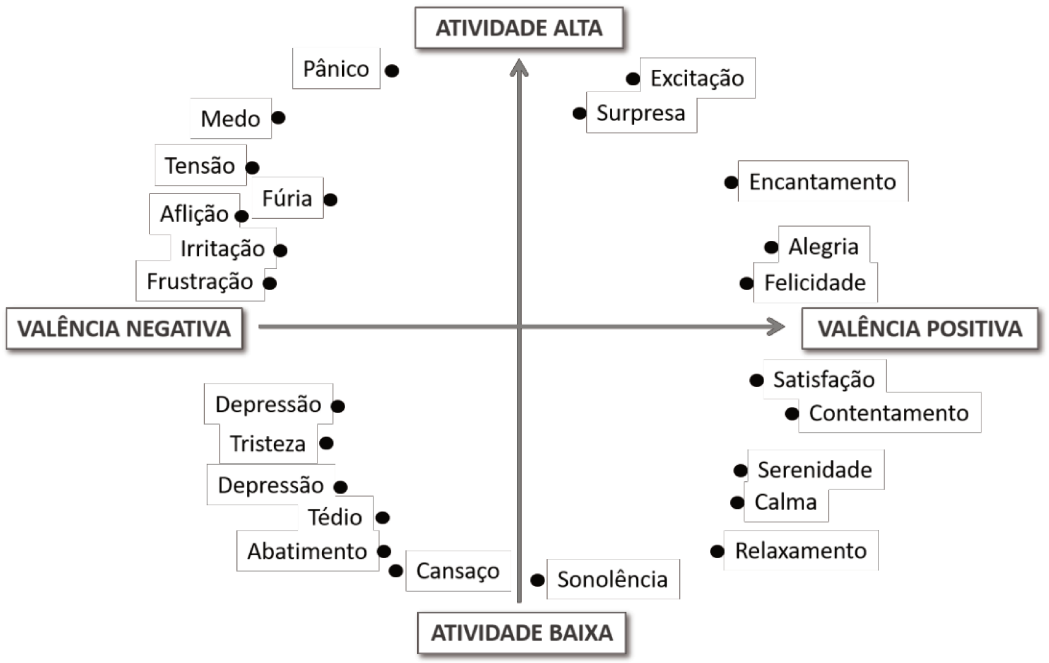

Figura 2. Modelo Circumplexo de Afeto[42].

As classificações previamente apresentadas retratam a concepção ocidental sobre as emoções. Como viés inovador do presente estudo, propõe-se a aplicação do método das Mandalas das Emoções (ME), desenvolvido pela Dra. Li Hui Ling[44], cuja concepção deriva de conceitos da Medicina Tradicional Chinesa (MTC).

As Mandalas das Emoções: enfrentamento das emoções

A Medicina Tradicional Chinesa propõe métodos para prevenir doenças, melhorar o físico e prolongar a vida. Nos primórdios da humanidade, a falta de conhecimento favoreceu a noção do sobrenatural para tentar entender os fenômenos do universo. Ocorrências naturais ou climáticas, os fatos da vida - doença, cura e morte foram interpretados no contexto do divino, sagrado.

Segundo a MTC, por meio das emoções, o indivíduo expressa como se sente tanto em relação ao corpo quanto à mente[44]. Na definição de bem-estar segundo a MTC, não basta a ausência de queixas físicas, mas uma harmonia nas esferas física, emocional e mental. Nesse sentido, as Mandalas das Emoções aplicam a teoria dos 5 movimentos, 5 emoções, 5 cores, Ying/Yang e as 5 direções[44].

Na Medicina Tradicional Chinesa existem as 5 direções, que são o leste, oeste, sul e norte e, no meio, chamado centro. Esse centro corresponde ao meridiano do estômago, baço e pâncreas, e à analogia de que a pessoa se alimenta, transforma o alimento para se fortalecer e, depois, os resíduos vão para o intestino, que os elimina na forma de fezes.

Dessa forma, o método abarca esse conceito de transformação como o ponto central de sua prática. As mandalas sempre têm um ponto central, o qual representa o objetivo a ser atingido. Por esse motivo, utiliza-se o nome Mandala para o método.

Outro conceito que deriva da Medicina Tradicional Chinesa são seus meridianos. O método se inicia com a mandala verde (primavera), que vibra funcionalmente o meridiano do fígado e da vesícula. Depois, o meridiano da mandala vermelha (verão), o meridiano do coração e pericárdio, intestino delgado. A mandala amarela, do alto verão, corresponde ao baço, pâncreas e estômago. Na sequência, a mandala branca representa o outono, pertence ao meridiano do pulmão e intestino grosso. A última, mandala preta, corresponde ao inverno, meridiano do rim e bexiga.

Esse método utiliza cinco pedras coloridas, do tamanho de uma noz, as quais são colocadas ao redor dos pacientes e, em algumas vezes, sobre o

abdômen da pessoa[44], sendo que cada pedra corresponde a uma das cinco emoções, com sua valência positiva ou negativa.

Figura 2. Ordem das mandalas de acordo com os conceitos da Medicina Tradicional Chinesa.

Dessa forma, a pessoa escolhe uma emoção que ela deseja entender, digerir e transformar. Essa emoção é colocada no meio. Por isso, temos 5 mandalas. A figura 3 ilustra o posicionamento das pedras para formar cada mandala.

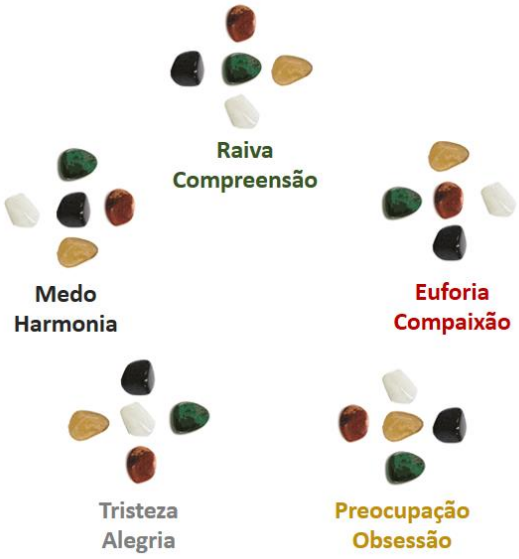

Figura 3. A disposição das pedras forma as cinco mandalas, sendo que sua cor é definida pela cor da pedra posicionada ao centro.

No quadro 1, descreve-se sobre as emoções atribuídas a cada mandala, com seu aspecto negativo (yin) e positivo (yang) e o construto conceitual de cada mandala.

Quadro 1 – Mandalas e suas respectivas cores, descrição e emoções relacionadas, no âmbito positivo e negativo.

Yin (negativo)	Yang (positivo)
Mandala verde	
Raiva	*Compreensão*
A mandala verde está ligada com o nascimento, com brotar, nascer, início da vida, introdução, com a primavera.	
Mandala vermelha	
Euforia	*Fé, esperança, compaixão*
A mandala vermelha está ligada com a adolescência, o desenvolvimento, crescimento, e representa o verão.	
Mandala amarela	
Preocupação, Obsessão	*Gratidão*
A mandala amarela representa o período da vida adulta, da colheita dos frutos, do alto verão, período de colher resultados.	
Mandala branca	
Tristeza, Melancolia	*Alegria*
A mandala branca corresponde à fase adulta, ao outono, período de reflexão/discussão.	
Mandala preta	
Medo	*Harmonia, Coragem*
A mandala preta representa o período da terceira idade, de conclusão, fechamento, corresponde ao inverno.	

O ponto central do método tem por intuito acolher as emoções e desenvolver a capacidade de reflexão, por meio de estratégias individuais e em grupo. A nível individual, a Dra. Li Hui Ling desenvolveu a estratégia de conforme descrita no anexo I, “Mandalas of Emotions for Add-on Therapy for

Self-Healing and Resolution of Internal Conflicts in Cancer Treatment". Nesse estudo, relata-se o uso do método com uma paciente com câncer, de forma a mediar o reconhecimento e discriminação das emoções, assim como a melhora no enfrentamento da condição clínica e do tratamento oncológico. Esse estudo de caso ocorreu a partir do primeiro semestre de 2015 até outubro de 2016, com o registro sobre a evolução clínica da paciente em tratamento oncológico e a estratégia de aplicação do método Mandalas das Emoções, com foco no controle emocional.

De maneira sucinta, são descritas nove etapas conceituais do processo de reconhecimento das emoções: identificar, acolher, aceitar, acessar, revisitar, compreender, ressignificar, refletir e abrir para nova visão. Essas etapas são utilizadas no estudo descrito no anexo II, para a composição dos processos sonoros.

No contexto da prática clínica, contudo, essas etapas não são explanadas ao paciente. A este, explicam-se os conceitos das Mandalas e as suas respectivas emoções, conforme constam no quadro 1. Essa explicação foi feita no caso descrito no anexo I e no estudo longitudinal com pessoas com epilepsia e seus cuidadores no anexo III. Com relação à prática com as mandalas, a técnica será descrita a seguir.

Em primeiro lugar, pergunta-se ao paciente sobre como está se sentindo e sobre qual emoção gostaria de trabalhar durante a prática, de maneira que este escolha uma emoção dentre aquelas descritas pela técnica das Mandalas (Quadro 1).

Ao paciente, solicita-se também que classifique seu perfil escolhendo entre três opções: sonhador, emotivo ou racional. Esse perfil autorreferido determinará o posicionamento das mandalas. Para o perfil sonhador, as pedras serão posicionadas nos pés; para o perfil emotivo, no abdômen e, por último, para o perfil racional, acima da cabeça. Esse posicionamento é feito com o paciente deitado. Existem outras possibilidades de posicionamento, como sentado em cadeira, sentado no chão com as pernas cruzadas, mas não foram técnicas abordadas nos estudos de aplicação individual (capítulo 3 e anexo I) da presente tese.

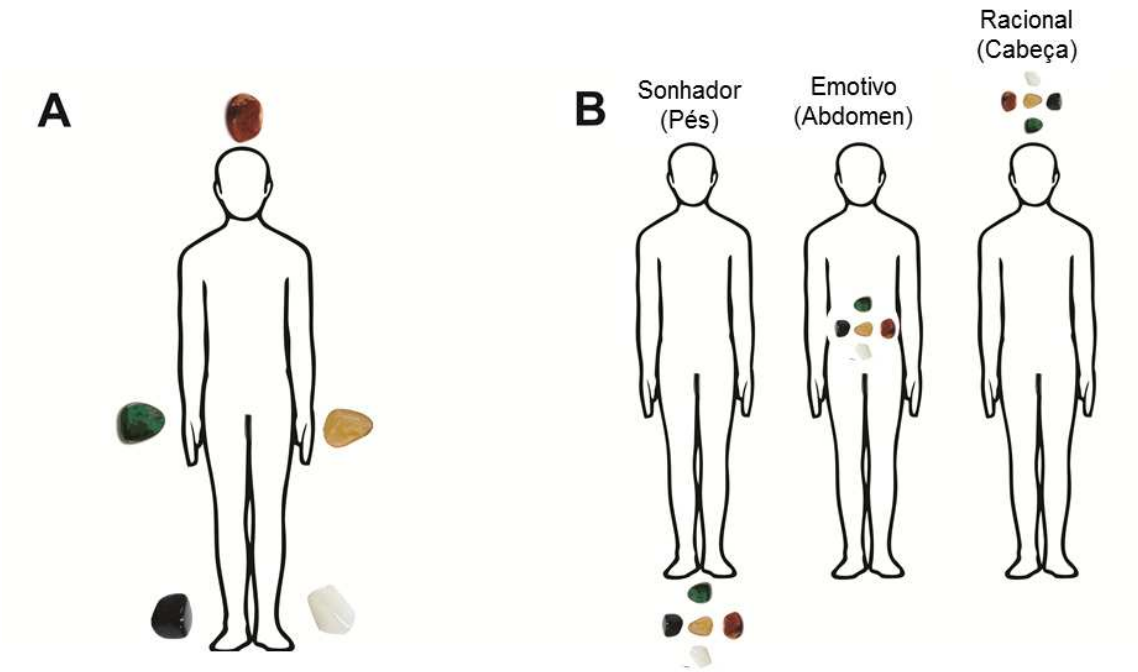

Figura 4. Posicionamento das pedras das Mandalas das Emoções durante o procedimento chamado da Harmonização, em A, e durante a aplicação da emoção escolhida, em B.

No primeiro momento, realiza-se o passo chamado “Harmonização”, com a mandala conforme figura 4A, posicionada ao redor do corpo do paciente, em posição deitada. Neste procedimento, o paciente deve fechar os olhos e prestar atenção na respiração durante 5 minutos, com o intuito de acalmá-lo, reduzindo eventuais interferências que possa ter sentido até sua chegada na consulta, como problemas no transporte ou outras preocupações. Em segundo lugar, a mandala correspondente à emoção escolhida é posicionada de acordo com o perfil autorreferido, conforme figura 4B, na qual ilustra-se a mandala amarela. A mandala é posicionada de maneira que, se o paciente a observar, estará no sentido correto para sua visualização. No caso ilustrado, a pedra amarela fica posicionada ao centro, seguida da pedra branca, acima; a pedra, à direita; a verde, abaixo; e a vermelha, à esquerda; fechando o ciclo.

O capítulo 3 da presente tese, por sua vez, no formato de manuscrito em preparação, apresenta o estudo clínico randomizado sobre as Mandalas das Emoções. Este estudo teve por intuito avaliar o efeito agudo do método, com uma aplicação de 15 minutos para pessoas com epilepsia e seus cuidadores.

Dessa maneira, o foco da avaliação foi o de capturar a resposta qualitativa imediata após esse estímulo cognitivo-comportamental.

Nesse sentido, a hipótese investigada é que as Mandalas das Emoções, especialmente ao paciente com epilepsia, poderiam trazer à consciência as emoções em um breve intervalo de tempo.

Utilizando-se o estímulo elétrico como um paralelo ao estímulo cognitivo, pode-se exemplificar um caso descrito por Gloor[45] sobre a reação imediata de um paciente com epilepsia (22 anos, masculino), a um estímulo na amígdala direita de 2,8 segundos a uma baixa intensidade de 1 mA. Importante destacar também a complexidade em se capturar e descrever a resposta ao estímulo. Abaixo, a descrição do caso segue como tradução livre da versão em inglês.

> *O paciente mantinha acompanhamento no Montreal Neurological Institute desde a infância pois ele havia sofrido de crises recorrentes que não respondiam ao tratamento. Então, considerou-se realizar uma intervenção cirúrgica. Como seu eletroencefalograma mostravam anormalidades epileptiformes bilaterais, eletrodos intracerebrais foram implantados nos lobos temporal e frontal pelo médico Dr. André Olivier. Esse procedimento teve como intuito facilitar a identificação do local da origem da crise do paciente antes do tratamento cirúrgico da epilepsia. Os eletrodos, que tinham múltiplos contatos, gravavam informações de áreas corticais superficiais e profundas do lobo frontal e temporal, assim como de estruturas límbicas de ambos lobos temporais. O último incluiu a amígdala, o hipocampo, e o giro parahipocampal em ambos os lados.*
>
> *O paciente havia sido instruído a relatar qualquer alteração, quando avisado que a estimulação havia iniciado. Imediatamente após o estímulo, ele disse "Sim". Quando questionado sobre o que ele havia sentido, ele relatou dificuldade em descrever, disse ter sentido uma sensação parecida com "cair na água". Quando foi estimulado a discorrer mais sobre isso, ele descreveu que parecia ter algo cobrindo seus olhos, nariz e boca. Quando o médico perguntou se era assustador, o paciente respondeu "Sim e não". Ele também descreveu que era algo estranho, e que o lembrava de pequenas crises, aos quais ele se referiu como "petit mals" (pequeno mal). Não havia alterações no eletroencefalograma em resposta a esse estímulo. A estimulação foi então repetida, mas nesse momento o paciente não foi avisado que o estímulo seria aplicado. A intensidade foi a mesma e a duração do estímulo de 2,4 segundos. Tão logo a estimulação foi ligada, o paciente exclamou "Agora", e adicionou "Poderia fazer isso de novo, doutor?". Quando questionado o motivo que o levou a solicitar isso, ele disse que, no momento que iniciou, ele tinha as palavras "na ponta da língua" para*

descrever a sensação, mas logo depois não conseguiu. Novamente, não houve pós-descarga.

A estimulação foi repetida mais uma vez, sem avisar o paciente, mas mantida por 4,4 segundos dessa vez. O paciente abriu sua boca, com um olhar atônito, sentou-se na cama e disse que agora sabia do que se tratava. Ele teve a sensação de estar em um pique nique no Brewer Park em Ottawa, e contou: "Uma criança estava vindo até mim para me empurrar para a água. Era uma certa hora, um dia especial durante as férias de verão e o garoto ia me empurrar para a água. Eu fui empurrado por alguém mais forte que eu. Eu tive essa mesma sensação quando eu tive o 'petit mals'". Ele chamou de uma sensação ruim. De novo, não houve pós-descarga. Quando questionado, ele disse que isso havia sido um evento real na vida dele. Ele lembrou alguns detalhes adicionais tais como quando a pessoa, um grande menino, empurrou-o para dentro da água de tal maneira que sua cabeça submergiu e manteve-a dentro da água. Quando questionado se ele se viu sendo perseguido pelo menino durante o estímulo, ele disse que não, mas havia a sensação como se ele estivesse naquele momento e tivesse sido perseguido. Esse evento aconteceu quando ele tinha 8 anos de idade, e ele disse que suas crises começaram pouco tempo após. Mais tarde, ele adicionou que havia outros momentos na vida dele que se tornaram parte das crises. Todos esses tinham em comum sua relação com algum fato desagradável ou amedrontador.

No caso descrito acima, ao receber o estímulo na amígdala, o paciente relembra a sensação ruim de uma experiência da infância, semelhante à que vivencia durante as crises. Nesse sentido, as Mandalas das Emoções, apesar de não constituírem um estímulo elétrico, podem figurar como uma proposta de método cognitivo-comportamental, de fácil aplicação e compreensão, abrindo a possibilidade para o paciente estimular o reconhecimento e entendimento de sensações e momentos que despertam emoções.

Durante a aplicação das Mandalas das Emoções no estudo randomizado caso controle (capítulo 3), notou-se que o ambiente do ambulatório de neurologia é, inevitavelmente, permeado por sons e ruídos que podem interromper o processo de concentração nas emoções exigido pelo método das Mandalas. Por esse motivo, além dos objetivos da presente tese, e como forma de contribuir para o desenvolvimento do método, realizou-se um projeto em parceria com o Núcleo Interdisciplinar de Comunicação Sonora (NICS), para a

elaboração e validação com especialistas de processos sonoros para as Mandalas das Emoções.

O anexo II descreve essa trajetória por meio do artigo apresentado como comunicação oral no 14th International Symposium on Computer Music Multidisciplinary Research (CMMR) Sound, Music and Motion realizado em Marseille (14-18 de outubro de 2019). Esse estudo parte da motivação de criar uma experiência imersiva por meio do som, de maneira a reduzir interferências sonoras externas ao consultório em um serviço de saúde, assim como possibilitar o uso dos processos sonoros às pessoas com deficiência visual.

Nesse estudo, atribui-se o nome de “processo sonoro”, uma vez que se replica o processo de reconhecimento das emoções. Nesse projeto, os especialistas em ME, que as utilizam há mais de 2 anos (n=8 pessoas), foram recrutados para avaliar os processos sonoros. O objetivo da participação dos especialistas é avaliar a percepção sobre o processo sonoro e adequar os parâmetros para aproximá-lo dos conceitos originais das ME. Os especialistas foram expostos de maneira cega e aleatória aos processos sonoros. A medida utilizada para criar os processos sonoros, o modelo circumplexo, foi também utilizada para sua validação. Assim, para cada processo sonoro, o especialista atribuiu uma posição na escala de valência e de alerta e descreveram sobre a emoção evocada pela música a partir das perguntas: “Qual a cor, som e de onde a emoção surge (órgão ou região do corpo)?”. Essa apresentação dos processos sonoros possibilitou aplicar ajustes e adequações dos processos sonoros a partir do feedback dos especialistas.

OBJETIVO GERAL

Estudar sobre as emoções de pacientes com epilepsia e seus cuidadores e estratégias para sua expressão e enfrentamento.

OBJETIVO ESPECÍFICOS

1. Analisar qualitativamente as causas de sofrimento psíquicos no paciente com epilepsia e seus cuidadores por meio do grupo Dialogando com as emoções.
2. Traduzir os resultados do estudo anterior para a expressão artística, como uma maneira inovadora de difundir o conhecimento sobre a epilepsia.
3. Avaliar o efeito agudo das Mandalas das Emoções como uma possibilidade de método para reconhecer as emoções.

METODOLOGIA

Durante esse projeto de doutorado, foram realizados três estudos, de acordo com os objetivos acima descritos:

Grupo "Dialogando com as emoções"

A coleta de dados foi realizada com pacientes e acompanhantes com consulta no Ambulatório de Neurologia de um Hospital Universitário, na data da consulta, às quintas-feiras das 12h-13h, com o apoio de duas enfermeiras e uma psicóloga para promover o apoio e a construção do conhecimento sobre a doença. O grupo semanal com 1 hora de duração, em média 10 participantes por sessão, encontros semanais por 1 ano, total de 50 relatos analisados, com a aprovação pelo Comitê de Ética: 35679314.5.0000.5404

Dentre as perguntas diretivas durante o grupo, pode-se citar: nome, idade, procedência; sobre as crises: tipo, frequência, severidade, impacto, efeito pós-ictal das crises; quando começou a epilepsia, se sabe qual é a causa; o que é epilepsia; se tem dificuldade no escola e/ou no trabalho; vocês falam que tem epilepsia?. Após o consentimento dos participantes, foi realizada a gravação e transcrição dos áudios para análise de conteúdo por temas.

A análise de conteúdo, em primeiro lugar, inicia com a leitura flutuante, seguida da leitura direcionada, com foco nas dificuldades psicossociais. Em segundo lugar, ocorre a exploração do material, com o desmembramento do texto em categorias. E, por último, ocorre o tratamento dos dados e interpretação, com inferências com uma abordagem qualitativa, trabalhando com significados[46-48].

Quadro 2 – Etapas da análise de dados

Etapas	**Ações**
1ª etapa: Pré-análise	**Leitura flutuante** **Leitura direcionada** (foco nas dificuldades psicossociais)

2ª etapa: Exploração do material	Desmembramento do texto em **categorias**.
3ª etapa: Tratamento dos dados e interpretação	Inferências com uma abordagem variante/qualitativa, trabalhando com **significados.**

Divulgação dos resultados através do espetáculo "Perspectiva"

A partir das transcrições, os resultados foram analisados com o intuito de fornecer material para a produção de uma apresentação artística baseada na metodologia de disseminação da produção científica através da arte, a Arts-Based Knowledge Translation strategy[49].

Esse método utiliza a classificação de quatro tipo de estratégias de tradução de arte em conhecimento, sendo estas passivas ou ativas, precisas ou subjetivas. No presente estudo, utilizaram-se mensagens-chave subjetivas, retratadas de forma ativa, por meio da dança contemporânea e das acrobacias aéreas, acentuadas pela iluminação e trilha sonora. Nesse sentido, o produto artístico tem como objetivo a criação de uma experiência ao público, que estimule o diálogo crítico e questionamento de conceitos[49].

Mandalas das emoções: estudo randomizado caso controle

Em terceiro lugar, foi realizada a principal pesquisa, também no Ambulatório de Neurologia do Hospital de Clínicas da Universidade Estadual de Campinas (HC-UNICAMP). Foram recrutados 110 voluntários às quintas-feiras das 11h às 15h. Os critérios de inclusão para este estudo foram: homens e mulheres em tratamento no ambulatório de epilepsia, com idade entre 18-60 anos, e/ou acompanhantes e familiares de pacientes. Todos os voluntários selecionados preencheram o termo de consentimento livre e esclarecido.

Os participantes foram convidados na recepção do ambulatório e, ao manifestar interesse em participar, foram referenciados à equipe de pesquisa. A equipe, composta por cinco pesquisadores, foi dividida em dois grupos: enquanto três pesquisadoras realizavam a entrevista antes e após a intervenção, duas outras aplicavam a intervenção, as quais dividiram os grupos

de participantes em “controle” e “intervenção com as pedras”, garantindo o sigilo dessa divisão perante os demais integrantes da equipe.

Antes da intervenção, foi realizada uma breve entrevista para coletar dados demográficos como: nome, idade, assim como sobre a organização emocional do participante, dentre os seguintes tipos: “pé no chão” (racional), sonhador, emotivo, e sobre a emoção prevalente no seu contexto atual, dentre uma lista (raiva, ansiedade, euforia, preocupação, medo, compreensão, compaixão, gratidão, alegria, paz).

Os participantes foram divididos aleatoriamente de acordo com sua ordem de chegada, em dois grupos: controle e intervenção com as Mandalas das Emoções. Ambos os grupos receberam as mesmas recomendações iniciais: permanecer deitado e prestar atenção em sua respiração.

Ao grupo “intervenção”, o protocolo consistiu na colocação de cinco pedras ao redor do participante por 5 minutos, etapa chamada de Harmonização. Neste período, o paciente foi orientado a fechar os olhos e prestar atenção na respiração, reduzindo eventuais interferências ou outras preocupações.

Após finalizada a Harmonização, perguntou-se ao paciente “Como você está se sentindo?”. Após, iniciou-se a segunda etapa, com o posicionamento da mandala correspondente à emoção escolhida de acordo com o perfil autorreferido, com duração de 10 minutos. A pedra é de material mineral, inerte e mantido em temperatura ambiente.

No protocolo para o grupo “controle”, o paciente foi orientado a permanecer deitado e prestar atenção em sua respiração. Após 5 minutos, perguntou-se ao paciente “Como você está se sentindo?” e foi solicitado que o paciente continuasse deitado e prestando atenção em sua respiração.

O tempo total de ambos os protocolos foi de 15 minutos, o mesmo para os grupos intervenção e controle.

Em seguida, ambos os grupos responderam a um questionário individual composto por questões semiestruturadas acerca do grau de relaxamento, alterações e sensações após a experiência.

RESULTADOS

Os resultados da tese serão apresentados em três capítulos, conforme listados abaixo:

Capítulo 1: “Dialogue with Emotions” through the Eyes of Patients with Epilepsy and Caregivers por Gabriela Salim Spagnol, Jéssica Elias Vicentini, Isilda Sueli Andreolli Mira de Assumpçao, Li Hui Ling, Li Li Min publicado no livro The Patient-Doctor Dynamics, editado por Jytte Holmqvist.

Capítulo 2: Arts-based knowledge translation in aerial silk to promote epilepsy awareness por Gabriela Salim Spagnol, Carolinne Yuri Tagami, Gabriela Bagattini de Siqueira e Li Li Min.

Capítulo 3: Randomized controlled trial to assess short results of Mandalas of Emotions, por Gabriela Salim Spagnol, Li Hui Ling, Jéssica Elias Vicentini, Li Shih Min, Nelson Filice, Li Li Min.

Capítulo 1

“Dialogue with Emotions” through the Eyes of Patients with Epilepsy and Caregivers, publicado no livro “The Patient-Doctor Dynamics”

No trabalho anteriormente realizado sob a orientação do prof. Li Li Min, baseado no Projeto Demonstrativo de Epilepsia, sob os auspícios da OMS-ILAE-IBE no Brasil, desenvolveu-se uma abordagem de dinâmica de grupo chamada de “Dialogando com as Emoções” em um ambulatório de epilepsia, a partir do Grupo de Interação Social (GIS) e dos conceitos descritos por Li Hui Ling. Essa abordagem possui elementos que envolvem domínios físicos, psicológicos e sociais, todos ligados às emoções.

No ambulatório de Neurologia de um hospital universitário, observou-se que os pacientes chegaram antes do horário da consulta médica, portanto, havia um tempo de espera, no período entre 12h e 13h, em que os pacientes estavam disponíveis. Assim, o grupo foi organizado com um caráter voluntário e para fins de pesquisa, com frequência semanal, por uma hora, com aproximadamente dez participantes por sessão, durante um ano. Para fins de pesquisa, os relatórios foram registrados e analisados qualitativamente.

Temas específicos foram distinguidos nas gravações, como vergonha de ter uma crise, tipos e causas das crises de epilepsia, estigma e preconceito no relacionamento interpessoal, falta de conhecimento sobre etiologia e fisiopatologia, como proceder nos primeiros socorros, adesão aos medicamentos, cirurgia, segurança das atividades, práticas para diminuir a exposição aos gatilhos das crises, dificuldade para manter um emprego, déficits de memória, entre outros.

Durante o grupo, os pacientes puderam trocar informações e compartilhar sobre seu conhecimento sobre a epilepsia e seu manejo. Os profissionais de saúde desmistificaram e esclareceram conceitos errôneos. Os amigos e familiares próximos também se envolveram, ao compartilhar suas experiências, oferecendo apoio para lidar com questões relacionadas à epilepsia.

O estudo mostra que a estratégia do grupo “Dialogando com Emoções” pode ser uma maneira alternativa para pacientes e famílias vivendo com epilepsia superar barreiras e melhorar a qualidade de vida, fornecer

informações, acesso e assistência emocional. Nesse cenário, pacientes e cuidadores estão no mesmo nível de profissionais de saúde, que capacitam e incentivam os pacientes a procurar sua solução e entendimento sobre a epilepsia.

CHAPTER 4

"Dialogue with Emotions" through the Eyes of Patients with Epilepsy and Caregivers

Gabriela Salim Spagnol, Jéssica Elias Vicentini, Isilda Sueli Andreolli Mira de Assumpção, Li Hui Ling and Li Li Min

1 Introduction

Epilepsy is a leading neurological disorder worldwide, with a rate prevalence of between 4 and 10 per 1000 people in developed countries and between 7 and 14 per 1,000 people in low– and middle-income countries. The proportions in these limited income countries constitute nearly 80% of the 70 million people worldwide with this condition.[1] In Brazil, there are approximately three million people with epilepsy, and to this number are added 300 new cases per day.[2]

Epilepsy is operationally defined as two or more unprovoked seizures occurring at least 24h apart,[3] or an underlying cause with an increased chance of seizure occurrence.[4] This disorder is characterized by unpredictable recurrent seizures, which can vary in frequency.[5] Seizures are described as brief episodes of involuntary movement that may reflect temporary dysfunction of specific neurons (focal seizures) or of a wider area involving both cerebral hemispheres (generalized seizures).[6]

Approximately 70% of people with epilepsy can control their seizures if given the appropriate medical treatment. Nevertheless, the burden of epilepsy can be substantial and complex, resulting in challenges in autonomy with a large weight in the psychological, physical, social and economic aspects,

1 Savvas Hadjikoutis, et al, "Approach to the patient with epilepsy in the outpatient department," *Postgraduate Medical Journal* 81 (2005): 442–447.

2 Ana L.A. Noronha, et al., "Prevalence and Pattern of Epilepsy Treatment in Different Socioeconomic Classes in Brazil," *Epilepsia* 48 (2007): 880–885.

3 Commission on Epidemiology and Prognosis, International League Against Epilepsy, "Guidelines for epidemiologic studies on epilepsy," *Epilepsia* 34 (1993): 592–596.

4 Robert S. Fisher, et al., "ILAE Official Report: A practical clinical definition of epilepsy," *Epilepsia* 55(2014): 475–482.

5 Mary Jane England, et al., *Epilepsy across the spectrum: promoting health and understanding,* (Washington, DC: National Academies Press, 2012), 25–110.

6 Carlos A. M. Guerreiro, et al., *Epilepsia* (São Paulo: Lemos, 2000), 1–10.

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revealing difficulties not only for the patient, but also for his or her family. This has ultimately consequences either in school, work or social environments.[7] At the time of diagnosis, patients and relatives face uncertainties, which rise from the lack of knowledge, beliefs, stigma, and fear of discrimination.[8] When these issues are not properly addressed, they can lead to poor self-esteem in patients, restrictions, and overprotection from the caregivers.[9] Quality of life is poorer in people suffering from epilepsy compared to the general population, and there is reportedly a higher prevalence of comorbidities.[10]

According to a survey on stigma in epilepsy,[11] social inclusion has been defined to be a major problem, since only half of the patients considered themselves socially engaged. This number probably reflects the rate of patients free of seizures, knowing that patients suffering frequent seizures have lower chances of professional or academic engagement. Furthermore, psychosocial issues and prejudice about epilepsy are one of the biggest barriers faced by patients, especially during school life and later at work.[12]

Over the past decades, patients, families and health professionals have gathered in non-governmental associations and organizations in order to guarantee the rights and social inclusion of those with epilepsy, playing an important role in the support of people with epilepsy in the fight against prejudice. These organizations are able to articulate public policies to capture the needs of patients related not only to medical care, but also to the social and economic aspects of their lives.

As beliefs and myths about the disease perpetuate stigma, projects and campaigns such as "Epilepsy Out of the Shadows" under the auspice of the World Health Organization (WHO), the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), as well as the Purple Day sponsored by Anita Kauffman Foundation – play a crucial role in disseminating knowledge about epilepsy, in order to reduce stigma and prejudice. These

7 Peter M. Bradley and Bruce Lindsay, "Care delivery and self-management strategies for adults with epilepsy," *Cochrane Database Systematic Review* 23(2008): 1–7.

8 Juliana Caixeta, et al., "Epilepsy perception amongst university students: a survey," *Arquivos de Neuro-Psiquiatria*, 65 (2007): 43–48.

9 Noelene Weatherby-Fell, "Epilepsy and media: implications for those whose role is to educate," *Ethical Human Psychology Psychiatry*, 13 (2011): 134–148; Bruce P. Hermann, et al., "A comparison of health-related quality of life in patients with epilepsy, diabetes and multiple sclerosis," *Epilepsy Research* 25 (1996): 113–118.

10 Ibid.

11 Paula T. Fernandes, et al., "Stigma scale of epilepsy: validation process," *Arquivos de Neuro-Psiquiatria*, 65 (2007): 35–42.

12 Paula T. Fernandes, et al., "Teachers perception about epilepsy," *Arquivos de Neuro-Psiquiatria*, 65 (2007): 28–34.

initiatives also show the importance of patient engagement in narrating their stories of how to overcome prejudice and challenges. In this sense, the Purple Day – an international grassroots effort dedicated to increasing awareness about epilepsy worldwide – was motivated by a nine years old girl's own struggles with epilepsy.

In 2008, this girl, called Cassidy Megan, wrote a letter to the International Bureau of Epilepsy and The International League Against Epilepsy describing that when she was diagnosed with epilepsy, she felt scared, embarrassed and alone, since she thought she was the only kid with epilepsy.[13] She kept it a secret, afraid of what others might think. One year later, the Epilepsy Association of Nova Scotia paid a visit to her school to teach about epilepsy. She noticed her friends wanted to learn more. When they asked the presenter if she knew anyone with epilepsy, she told them yes. That was when Cassidy told her mom and teacher that they could reveal to people that she also had epilepsy. She was still scared, but knew she would have the support of her classmates. Cassidy's goal in creating the Purple Day is to get people talking about epilepsy in an effort to dispel myths and inform those with seizures that they are not alone. The Epilepsy Association of Nova Scotia came on board in 2008 to help develop Cassidy's idea which is now known as the Purple Day for epilepsy campaign. She chose the colour purple referring to lavender and the day March 26th as the landmark of epilepsy awareness. Today, the Purple Day has become an international movement – also celebrated in Brazil, during which stories of patients with epilepsy are shared and disseminated.

In the late 1990s, the concept of Narrative Medicine arose, established, among others, by Rita Charon. This concept holds that medical practice focused on patient should include "stories of illness" in order to understand the personal experience regarding the disease.[14] The systematic record and analysis of patient stories is one of the approaches to promote the learning of students and physicians. Thus, this study applies this concept to contribute in professional education, and especially to disseminate knowledge and break down prejudice.

Since the high prevalence and incidence of stigma perceived by the individual with epilepsy may negatively affect health-related behaviours, including treatment, coping, and self-management and the psychosocial difficulties affect not only patients, but also family members, this study aimed at establishing

13 Cassidy Megan, letter from author to the members of the International Bureau of Epilepsy and The International League Against Epilepsy, 31 January 2014.

14 Rita Charon, *Narrative Medicine: honouring the stories of illness* (Oxford: Oxford University Press, 2006), 250–288.

a group for patients and caregivers with healthcare professionals, in order to promote psychosocial support and exchange of experiences.[15] Based on previous successful initiatives in the fight against stigma in epilepsy, afterwards, the record of these meetings was transcribed, analysed and converted into articles and books to disseminate knowledge about epilepsy.

2 Methods

We observed that patients arrived at least one hour ahead of medical consultation time. For this reason, the group session was planned to take place during this period, adding value to the patient during his or her stay at the hospital. This weekly group session lasted one hour, with approximately ten participants per session, and meetings were held for one year. This study was approved by the local Ethics Committee.

Patients, family and caregivers were invited to join the group, and also to contribute in this research, by signing a consent form, after it had been explained that sessions would be recorded. Participation in the group was allowed even without the contribution of a volunteer in this study. This meant that excerpts from transcripts with the volunteer contributions would be excluded from our records. However, all those who were invited to participate in the group were also keen on contributing in the research and signed the consent form.

Regarding ethical concerns, this study did not present risks to volunteers, nor did it provide any direct benefits to participants. However, it presented social benefits, since we infer that a better understanding regarding the life of a person with epilepsy may help understand the difficulties and limitations of this disease, and also help motivate participants when listening to stories about clinical improvements and quality of life. All recordings remained confidential and anonymous.

3 Results

After each group session, recordings were transcribed and later analysed. They were grouped in themes as per their frequency of report.

15 Emily B. Leaffer, et al., "Psychosocial and sociodemographic associates of felt stigma in epilepsy," *Epilepsy Behaviour* 37 (2014): 104–109.

A ***Fear, Shame and Lack of Control***

This feeling was reported by patients in relation to several situations:

– Shame/fear of suffering from a seizure in a public place:

> In the beginning, I used to be terrified of having a seizure in public, as I had in the market once. Those around me warned the entire market, and lots of people surrounded me – when I woke up I saw them looking at me. So it was really embarrassing and I was always afraid of experiencing this situation again.

– Shame/fear of losing consciousness and control of bowel or bladder function during a seizure:

> I was stirring a pot on the stove, when I realized that I was not okay. A few seconds later, I tried to sit down, to lean on something. By the time I came back to my senses, my hand was holding the sink and the carpet was wet. I had had urine loss. I went outside to quickly wash the carpet ... and I started to wonder ... what had happened?

– Shame/fear of telling family members, friends, classmates and co-workers about epilepsy;
– Fear of not being able to carry out or keep a job;
– Fear/shame of not being able to work or perform specific tasks, nor to carry out daily activities such as self-care and cooking without assistance.

B ***Restriction and Adaptation***

Patients often reported a feeling of limitation and of being "prisoners," as seen in this excerpt, followed by an adaptation phase:

> I have always had my independence, I could go anywhere, work, and all the sudden [after epilepsy was diagnosed], I lost this freedom. Sometimes I go out without letting people know, because I was feeling trapped. What kind of life will I be able to live? Will I be able to do anything I like? It is like I said earlier, I don't want to stay home, I get bored easily, so I look for something to do, then it [the restriction after epilepsy was diagnosed] was a shock. Sometimes I have stupid thoughts in my mind, but after a couple of days, I start to realize that I am actually still able to do some things [related to leisure, cooking and daily activities]. – patient A.

C *Stigma and Prejudice*

Patients and family narrated stories concerning the interpersonal relationships in social environments, such as school, the workplace and the home, where stigma and prejudice were expressed verbally or in attitudes that could culminated in social isolation for those with epilepsy.

D *Lack of Knowledge*

Participants posed questions that showed gaps in their knowledge concerning:

- The etiology and pathophysiology of epilepsy;
- The process of clinical diagnosis and importance of exams such as electroencephalogram, telemetry and magnetic resonance;
- How to proceed during a seizure;
- Different types of seizure and how to identify them;
- About the surgery: patients reported fear to submit to the surgery since they did not understand the procedure and they had false expectations concerning outcomes after surgery, such as no need to continue medication treatment.

These questions were either responded by a healthcare professional (nurse or psychologist) or by other patients and participants, who had successful life experiences and knowledge to share.

E *Medication Compliance*

Medication compliance refers to whether patients take their medications as prescribed and to whether they continue to take a prescribed medication. Stories reflected serious misconceptions about the treatment, such as the idea that in the absence of a crisis, medication could be suspended, but effective strategies to sustain the treatment were also reported, such as visual reminders and association of the medication schedule with meals provided to prevent lapses.

F *Safety*

Strategies to continue activities at work, in the leisure time and/or at home without compromising safety (I), as well as practices to decrease exposure to seizure triggers (II):

> I – 'We [*patient A's family*] have never forbidden him to go out. Sometimes he has a seizure in a public place, but people already know him and help him out. There is also a very dangerous staircase at our home, so we ask him not to climb it without supervision, and we asked him not to drive anymore, because it is not safe' – *patient A's son*.

II – 'I met a guy who could not go to night clubs [*because of light shows that are seizure triggers*]. I realized that when he had little sleep or when he drank too much coffee, he had more seizures. So he changed his habits'.

G *Memory Deficits, Especially after Seizures*

It is a strange thing [*waking up after a seizure*]. On my daughter's wedding, I could not remember how I had arrived at the venue. I only remember her with a piece of handkerchief drying my lips. I remember we were on a familiar road, and I thought I was okay. But I was having a seizure.

3 Discussion

A *Fear, Shame and Lack of Control*

Fear and shame can precede any situation of discrimination and become common in daily living with epilepsy and commonly evolve into behavioural changes (shame, insecurity, isolation) and greater difficulties in psychosocial adjustment.[16] In our study, these emotions were mostly related to the seizure, restrictions that epilepsy may have on daily activities and the prejudice one may face when sharing with others about epilepsy. These attitudes are reinforced by lack of knowledge and prejudice. Public education can change perceptions, and consequently, lead to greater social acceptance of those with epilepsy.

B *Restriction and Adaptation*

Patients in our study reported that epilepsy and its treatment implied restrictions and adaptations in their daily lives. Several studies describe that epilepsy impacts on relationships, social life, employment, and plans for the future.[17] In our study, most narratives depicted a scenario in which patients and family members followed a similar route: after receiving the diagnosis of epilepsy and

16 Fernandes, et al., "Stigma scale of epilepsy: validation process," 35–42.

17 Gus A. Baker, et al., "Quality of life of people with epilepsy: a European study" *Epilepsia* 38 (1997): 353–362; Ann Jacoby, et al., "Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma," *Epilepsia* 45 (2004): 1405–1415; Marju Herodes, et al., "Epilepsy in Estonia: a quality-of-life study" *Epilepsia* 42 (2001): 1061–1073; Arthur Kleinman, et al., "The social course of epilepsy: chronic illness as social experience in interior China," *Social Sciences Medicine* 40 (1995): 1319–1330.

its treatment there was a general feeling of restriction and fear related to the new life conditions. But the following experiences also lead to new possibilities, mutual support and resilience to adapt, in order to pursue welfare for patients suffering from epilepsy and personal fulfilment.

C *Stigma and Prejudice*

When it comes to psychosocial difficulties, stigma is the first aspect to be addressed. According to Goffman (1963),[18] the stigmatized person is considered to be having different characteristics and receives a different treatment by the community, which assumes prejudiced concepts in relation to this particular person. It is an aspect which influences the person's health in a global way, including their physical and psychological well-being.

A study by Fernandes and colleagues[19] described a negative correlation between level of education (illiterate to higher education) and stigma score in Brazil, in which as the level of education rises, the perception of stigma decreases. The same pattern was described for socioeconomic classes, suggesting that lack of knowledge is one aspect of stigma, since information access increases according to educational and socioeconomic level. However, another possibility is that people may have offered "politically correct" answers. Also in this study, an unexpected finding was the difference in level of epilepsy stigma between women and men, with women demonstrating higher stigma perception.

Misconceptions about epilepsy are still common and, in some cases, may imply superstitious perceptions, such as the belief that epilepsy is "God's punishment." In this sense, Fernandes and colleagues state that the perception of epilepsy is influenced by each person's beliefs, particularly by the religious faith.[20] When comparing different religious groups, Fernandes and colleagues[21] observed the lowest scores for those who declared an affiliation with Spiritism, which is a doctrine based on belief in superior spirits and communication with these spirits through a medium.

D *Lack of Knowledge*

Seizure control is the starting point but not sufficient to ensure a normal life for these patients. When compared to people without epilepsy, patients with

18 Erving Goffman, *Stigma: notes on the management of spoiled identity*. (New York: Touchstone, 1963), 10–25.

19 Fernandes, et al., "Stigma scale of epilepsy: validation process," 35–42.

20 Ibid.

21 Ibid.

epilepsy appear to have a very different life, because they suffer greater social isolation, greater difficulty in social relationships, and higher unemployment rates, among others. It is important that people know what epilepsy is, what it implies, and what the psychological difficulties are, in order to decrease the burden of prejudice inflicted upon the patient and his/her family. In this context, we created the group dialoguing with the emotions, in order to give support to people with epilepsy, by promoting personal resilience, improved quality of life, and sharing emotions and experiences.[22]

E *Medication Compliance*

The available treatment that relies on the correct use of antiepileptic medication can control epilepsies in 70% of cases with a single drug, and, in 10% of cases, if medications are combined. Results of a systematic review of the literature by Meyer and colleagues suggest that there are dramatic global disparities in the care and treatment of epilepsy patients.[23] The reasons for this non-treatment are complex, and include: the wish for non-treatment, lack of knowledge about an existing treatment, an unprepared health system to treat the patients, and social stigma. In this sense, it is necessary to follow the hierarchy of care: low complexity epilepsy should be treated in primary care, and high complexity epilepsy in tertiary centres, where treatment plans could rely on a combination of drugs, new therapies, and surgical treatment.

F *Safety*

In Campinas, a city of one million people and with universal access to health care, the treatment gap (patient untreated or inappropriate medication regime) of people with epilepsy is 40%.[24] This means that almost half of the people with epilepsy are unprotected from the risk of injury or death as a result of crises. People with epilepsy need the support of those around them to secure safety conditions to sustain their daily activities at home, school and work.

G *Memory Deficits*

Memory deficit is one of the most common symptoms after seizures. As highlighted in the previous section, those surrounding people with epilepsy must

22 Humberto Maturana, *Ontology Reality* (Belo Horizonte: UFMG, 1997), 167–181.

23 England, et al., "Epilepsy across the spectrum: promoting health and understanding," 25–110.

24 Noronha, et al., "Prevalence and Pattern of Epilepsy Treatment in Different Socioeconomic Classes in Brazil," 880–885.

be sensible enough to provide not only safety precautions but also emotional support after seizures have occurred.

4 Conclusion

During these meetings, patients, family members and caregivers could exchange information and advice others to learn about epilepsy and its management, providing sympathetic understanding. Close friends and family showed engagement in sharing their experiences, providing support to deal with issues related to epilepsy. Further explanation on specific topics was covered by healthcare professionals, who demystified and clarified misconceptions and also mediated the group dynamic.

Sharing patient stories allows for making sense of their suffering and how it feels from the inside. Sharing stories offers a biographic and social context of the illness experience and suggests coping strategies, creating potential for personal development. In this sense, "Dialogue with Emotions" can be an alternative way for patients and families living with epilepsy to discuss and share their feelings. This is the first step in the process towards overcoming barriers and improving quality of life. In this setting, patients and caregivers are at same level as healthcare professionals, who empower and encourage patients to seek his/her own solution and ability to understand epilepsy.

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Capítulo 2

Arts-based knowledge translation in aerial silk to promote epilepsy awareness, publicado no Journal Epilepsy & Behavior

As estratégias de tradução do conhecimento baseado nas artes (ABKT) representam uma abordagem inovadora para disseminar resultados de estudos qualitativos, especialmente para abordar questões sociais, como estigma e preconceito, devido às lacunas de conhecimento. A epilepsia traz um forte impacto psicossocial ao paciente, familiares e cuidadores, e traz dificuldades para estabelecer relações sociais devido ao estigma.

No próximo estudo, narra-se a construção de uma dança aérea e contemporânea com base nos resultados do estudo qualitativo com pacientes com epilepsia (Capítulo 1), suas famílias e profissionais de saúde, denominado “Dialogando com as Emoções”. O uso de tecido aéreo foi uma metáfora da necessidade de quebrar barreiras impostas pela epilepsia. Nas acrobacias aéreas, os artistas, sem o uso de linhas de segurança, escalam o tecido e o utilizam para manobrar figuras difíceis, torções e quedas.

Nesse sentido, a coreografia denominada “Perspectiva”, com 15 minutos de duração, no total de 5 cenas, apresentou elementos relacionados ao sofrimento, dor, medo, isolamento social, seguidos de apoio mútuo, resiliência, adaptação e felicidade. Por meio de sua poesia cênica e acrobacias combinadas com efeitos especiais de iluminação e trilha sonora, essa coreografia representa o potencial de superar o sofrimento e experimentar a felicidade se as pessoas adotarem uma perspectiva diferente da epilepsia.

A parceria entre uma professora de acrobacias aéreas (GBS) e uma enfermeira envolvida neste estudo de epilepsia (GSS) deu origem a uma apresentação única em homenagem às pessoas com epilepsia, apresentada na abertura do XIV Encontro Nacional da Federação de Epilepsia (4 de março de 2016) e no Congresso BRAINN (13 de abril de 2016). Nessas ocasiões, houve uma grande comoção entre o público, incentivando novas discussões

nos dias subsequentes. Assim, essa apresentação promoveu discussões sobre epilepsia, disseminando resultados de pesquisas, promovendo empatia, compaixão e esperança.

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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 acrobacies).

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.

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 Archbald, 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 acrobacies). 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 acrobacies, establishing a bound 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 assessed in further research, since our proposal in this article is to present the method for knowledge translation into art.

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

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

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 Kılınç 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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Capítulo 3

Randomized controlled trial to assess short results of Mandalas of Emotions, manuscrito em preparação

O método chamado 'Mandalas das Emoções' apresenta como proposta facilitar o reconhecimento e o enfrentamento das emoções. Realizamos um estudo de controle de caso cego para avaliar os efeitos agudos do método ME. O protocolo está registrado nos ensaios clínicos, número NCT04220333.

Pacientes e cuidadores recrutados em um ambulatório de epilepsia com a aprovação do Comitê de Ética foram divididos aleatoriamente em grupos 'Controle' (n = 57) e 'Intervenção' (n = 53).

No grupo ME, cinco pedras coloridas (verde, vermelha, amarela, branca e preta) foram aplicadas de acordo com a emoção escolhida pelo participante. A avaliação individual realizada às cegas para quem recebeu a intervenção aplicou um questionário estruturado e escalas Likert sobre o grau de relaxamento e sentimentos pré e pós-experimento. O próximo capítulo traz a descrição completa do estudo.

Randomized controlled trial to assess short results of Mandalas of Emotions

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Abstract

Epilepsy is a chronic disease with a psychosocial impact on the patient. The method called 'Mandala of Emotions' (ME), derived from the Traditional Chinese Medicine, facilitates expression and awareness of emotions. In our pilot case study, the group "intervention with ME" managed to arouse their emotions and after the intervention felt lighter and relaxed at a higher frequency than the control group. We conducted a blind case control study to further assess usefulness of ME. The protocol is registered in Clinical Trials, number NCT04220333. Materials and Methods: Patients and caregivers recruited at an Epilepsy Outpatients Clinic with the approval of Ethics Committee were randomly divided into groups 'Control' (n=57) and 'Intervention' (n=53). In the ME group, five colored stones (green, red, yellow, white and black) were applied according to the emotion chosen by the participant. Individual assessment performed blinded to who received intervention applied a structured questionnaire and Likert-scales about the degree of relaxation and feelings pre- and post-experiment. Results: The Pearson's Chi-square test demonstrates that there is no significant association between the groups control and intervention analysed for sociodemographic variables (sex, age, employed/unemployed) or clinical (for patients with epilepsy) except for: sex of caregivers, age of epilepsy onset and therapeutic regimen. In relation to the clinical trial, there was a significant effect of the procedure performed [$F_{1,106}= 27.94$, $p < 0.001$]. This effect does not depend on intervention or control but caregivers reported higher values in the Likert Scale both before and after the procedure compared to patients [$F_{1,106}= 7.789$, $p= 0.006$]. There was no moment of evaluation*patient/caregiver interaction. Five minutes after the procedure began, participants from both groups (control and intervention) were asked "How are you feeling?" and the researcher registered as they reported physical and emotional changes. We classified their responses in categories, as "Yes" or "No" for referral of changes. We found a significant difference in the distribution of presence or absence of comments when comparing intervention and control [X^2 (1) = 11.97, $p <0.001$]. There is also a difference in the patient and caregiver groups for intervention vs. control as follows: caregivers X^2 (1) = 7.43, $p = 0.008$; patients X^2 (1) = 5.32, $p = 0.01$. Conclusion: When facing internal conflicts, patients may develop a blockage in self-ability, understanding of feelings and social withdrawal, implying directly in the way they express their emotions, desires and opinions. Mandalas of Emotions presents a potential as an integrative practice in this scenario. This study presents several limitations, as differences in sex distribution, religion status (which was not investigated), participants' anxiety, and sound disturbances in the corridor. Thus, in order to assess this potential, further studies may evaluate long-term effectiveness of Mandalas of Emotions.

Key Words: Epilepsy; traditional Chinese medicine; integrative health; complementary medicine.

Introduction

Epilepsy imposes a substantial emotional burden to patients and caregivers. The unpredictability of episodic seizure occurrences with loss of consciousness imposes driving and employment restrictions. Challenges in autonomy are part of complex mechanism underlying stigma in epilepsy (Bandstra, 2008; Fernandes, 2011; Leaffer, 2014; Herrmann, 2016). The consequence of stigma varies and can lead to the extreme of social isolation (Li&Fernandes, 2011, Mula&Sander, 2016, Fiest et al, 2014). Living with epilepsy stigma, felt or enacted, can result in mental health disorders. Stress and anxiety have been reported to be higher for children (Caplan, 2005) and adults (Stefanello, 2010) with epilepsy than control subjects. Johnson and colleagues (2004) estimate the lifetime prevalence of depression in association with epilepsy to be as high as 55%.

The quality of life is directly influenced by world region and income category, with lower country income level associated with worse quality of life, as described in a metanalysis of studies published between 2000 and 2015 by Saadi and colleagues (2016). Moreover, Szemere and Jokeit (2015) highlight quality and quantity of social interaction in professional and personal relationships as the main factors and predictors of well-being, happiness and life satisfaction.

Over the past decade, there has been a growing interest in applying integrative therapies to improve mental health and quality of life. Approaches of Traditional Chinese Medicine (Zhang et al, 2015), acupuncture (Kung, 2015), mindfulness (Van Dam et al, 2018) and yoga have been reported to improve mental health and quality of life in general. In patients with epilepsy, pooled results in systematic reviews are not conclusive due to several methodological factors (Roddis & Tanner, 2018).

We have experience of applying an integrative therapy named ‘Mandalas of Emotions’, developed by one of us (LHL), based on references from Traditional Chinese Medicine (TCM). The Traditional Chinese Medicine proposes methods to prevent diseases, enhance physique and prolonging life. In the early days of humanity, lack of knowledge favored the notion of the supernatural to try to understand the phenomena of the universe. Natural or climatic occurrences, the facts of life — disease, healing, and death were interpreted within the context of divine, sacred.

TCM establishes five stages to explain the cycle of life, which is integrated with the cycle of plants, changes of seasons and functional systems of the human body (Ling, 2013). The use of colored stones with a reference to TCM is a symbolic way to probe the emotional status of the human being, and at the same time to cognitively awakening them to a level of reasoning. The Mandalas of Emotions refers to five colors in accordance to the five stages or seasons (spring, summer, high summer, fall, winter). These establish a relation to the five functional systems (liver, heart, spleen and pancreas, lungs and kidney), and to five emotions (anger, joy/euphoria, concern/obsession, sadness/melancholy, fear) with its opposite correspondents (understanding, compassion, gratitude, enthusiasm, harmony) (Ling, 2013). See figures 1 and 2.

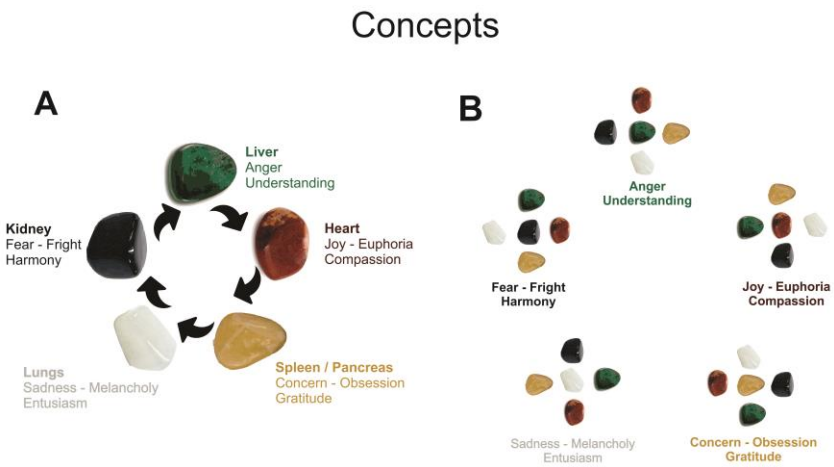

Figure 1. A. The basic cycle of mandalas is depicted in this image, in the sequence: spring/green, summer/red, high summer/yellow, autumn/white, winter/black. B. Each emotion corresponds to one of the five Mandalas depicted in the figure above.

In our pilot study, we applied ME in eight adult patients with epilepsy (Ribeiro et al, 2017). A qualitative unblinded assessment of their narrative and behavior changes yielded impressive results. All subjects reported some degree of understanding of their emotions and perception of physical changes as they felt lighter and relaxed after the ME. We conducted a randomized case control study to further investigate ME, with a blind assessment of the effects of ME using a structured quanti-qualitative questionnaire.

Materials and Methods

This is a case control randomized study, with parallel assignment. The protocol has been submitted and is registered in Clinical Trials, number NCT04220333, and this study has approval of local Ethics Committee (number 64276116.4.0000.5404).

Study participants

Patients and caregivers were recruited at an Epilepsy Outpatients Clinic between July and November 2017. Participants were invited to this research at the Outpatient clinic waiting room, and when they expressed interest, they were referred to the research team. Inclusion criteria for this study were: men and women treated in the epilepsy outpatient clinic, aged 18-60 years. Exclusion criteria were associated clinical conditions that prevented full comprehension of research procedures.

Volunteers signed the informed consent to participate in the study, answered a questionnaire with information about demographics, epilepsy history (age of onset, frequency, last seizure, medications). They described their emotional characteristics (intuitive, emotive, and rational) and how they felt at that moment. They were invited to choose an emotion from a list (Concern/obsession, Anger/irritation, Fear, Compassion, Sadness, Comprehension, Euphoria, Gratitude, Joy, Peace) to work on during the intervention.

Randomization consisted in allocating research participants, patients or caregivers, into two groups according to the order of their arrival at the Epilepsy Outpatients Clinic.

Research team

The team, composed of five researchers, was divided in two groups: three researchers performed the interview before and after the intervention, two others applied the intervention, which divided participants in two groups: "control" and "intervention", assuming the confidentiality of this classification, as expected in a randomized, case control, blind assessment of outcome study.

Both groups received the same initial recommendations: 'please, lie down, relax and pay attention to your breath'. The total procedure time was the same for both groups.

Arms and Interventions

Placebo Comparator: Control

Participants received the instruction: 'please, lie down, relax and pay attention to your breath' for 5 minutes. At this point, participants were asked “How are you feeling?” and then requested to continue relaxing and paying attention to their breath for the next 10 minutes. Soon after this procedure, individual assessment was performed blinded to who received intervention using a structured questionnaire and Likert-scales about the degree of relaxation and feelings.

Experimental: Intervention

The intervention protocol was divided in two steps: first, patients spent 5 minutes in the phase of “Harmonization” with five colored stones of a size of a walnut (green, red, yellow, white and black) placed around their bodies, according to the method of Mandalas of Emotions, as depicted in figure 2A.

Second, in accordance to the emotion chosen by the participant, a matching mandala was placed next to the feet, on the abdomen, or next to the head depending on the self-perceived personality type, intuitive, emotive and rational for the remaining 10 minutes (see figure 2B).

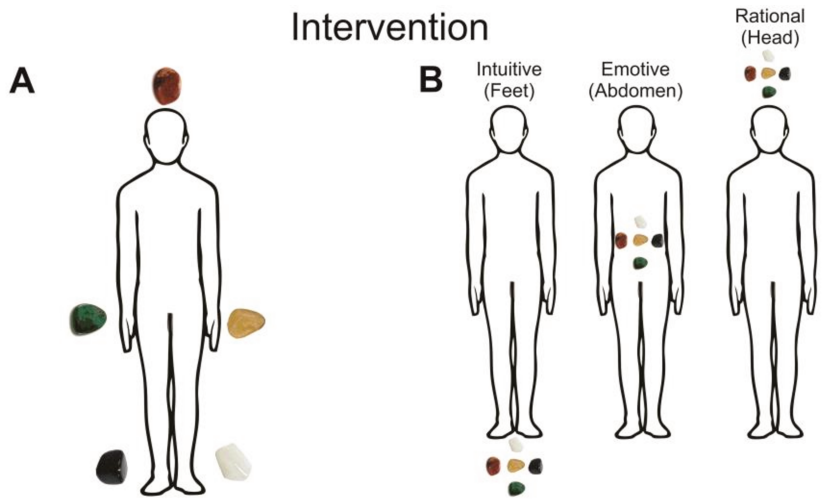

Figure 2. A. This step, called harmonization, corresponds to placing five stones around the patient as depicted in the figure above for five minutes. The patient received instructions as follows: “relax and welcome emotions that come in your mind, do not try to justify or rationalize. See emotions as a way of learning”. B. During the step ‘Mandala’, the stones were placed depending on the self-perceived personality type reported on the structured questionnaire, according to the above classification during 10 minutes. The patient received instructions to think and reflect upon the emotion he chose.

After experiment

Soon after the experiment, individual assessment was performed blinded to who received intervention using a structured questionnaire and Likert-scales about the degree of relaxation and feelings.

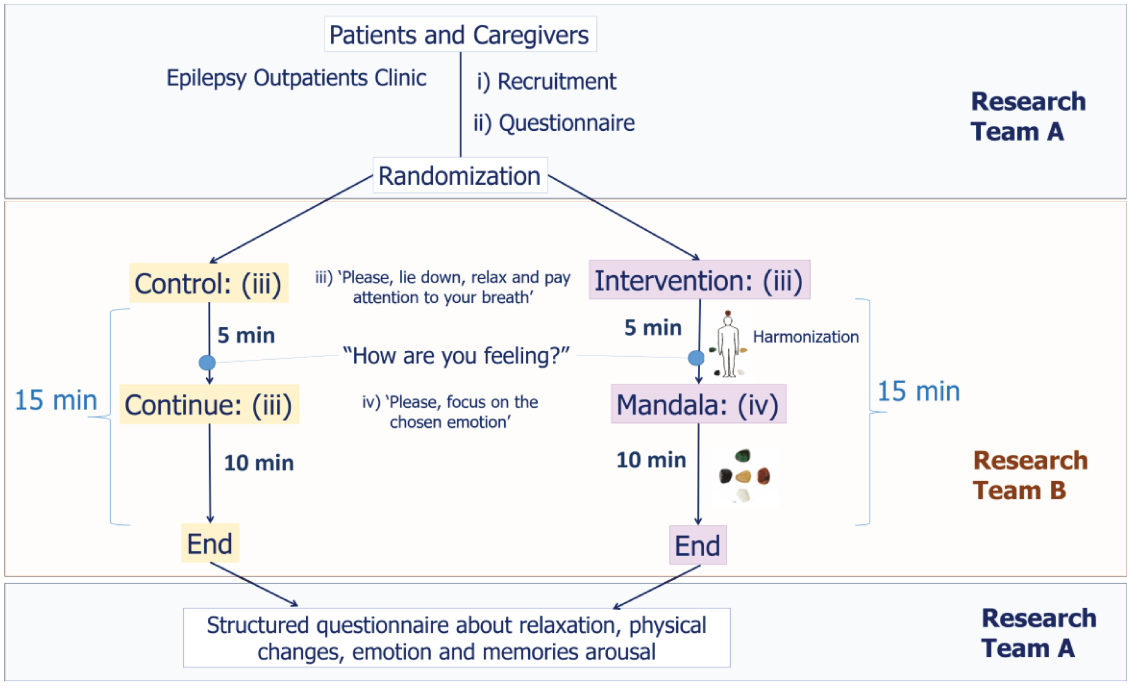

Figure 2. Research procedures.

Outcome Measures

Pre procedure Likert scale report

Before the procedure, researchers asked "How are you feeling?" and participants replied in a Likert scale from 1-Very bad to 5-Very good.

Perception of changes after 5 min of procedure

Five minutes after the procedure began, researchers applied the question: "How are you feeling?" and the researcher registered as they reported physical and emotional changes for both groups (control and intervention). No further measures or questionnaires were applied at this point.

Post procedure Likert scale report and qualitative questions

After the procedure, researchers asked "How are you feeling?" and participants replied in a Likert scale from 1-Very bad to 5-Very good. Researchers also applied a questionnaire with these questions: "Did you experience body changes / retrieval of memories / retrieval of specific images? Do you have any observations regarding the procedure? Researchers registered yes/no reply and participants description of changes. No further measures or questionnaires were applied after this procedure.

Statistical analysis

We first divided the groups and analyzed whether they differed in regard to sex, age, years of schooling, age of onset of epilepsy, time of last seizure, frequency of seizures per month, use of monotherapy and pharmacological response. Statistical analysis was conducted with SPSS using parametric tests (ANOVA for repeated measures) and non-parametric tests (Mann-Whitney) and Pearson's Chi-square test. Using ANOVA for repeated measures allowed to verify intra and intergroup comparisons. The test shows no serious violations that compromise the model. Content of patients' perceptions were analyzed according to themes and compared between groups (control vs. intervention).

Results

Study participants

This study included 110 volunteers, divided in two groups: 57 participants in the 'control' group and 53 in the 'intervention with ME' group. The Pearson's Chi-square test demonstrates that there is no significant association between the groups control and intervention analysed for sociodemographic variables (sex, age, employed/unemployed) or clinical (for patients with epilepsy) except for: sex of caregivers, age of epilepsy onset and therapeutic regimen (Table 1).

In the group of caregivers, there is a significant difference of sex distribution, with more females in the intervention group (13 females of 15 caregivers), when compared to the control group (10 females of 19 caregivers).

In regard to epilepsy onset, intervention patients present a higher media of 15 years of age (from 0 to 50 years old), in comparison to control, with 8 years of age (from 0 to 32 years old) ($U=967.0$, $p=0,01$). Most patients from control group are copying with epilepsy since childhood, while the intervention group faces this condition since adolescence. Related to therapeutic regimen, 13(34%) of patients in the intervention group have a monotherapy regimen, whereas in the control group, there are 29(76%) use more than one medication.

Table 1. Sociodemographic and clinical variables of research participants, Campinas, 2019

	Patients		**Test statistics**	**Caregivers**		**Test statistics**	**Total**		**Test statistics**
	Intervention (n=38)	Control (n=38)		Intervention (n=15)	Control (n=19)		Intervention (n=53)	Control (n=57)	
Age	42±13.0	42±16.5	T (74)= -0.06, p= 0.05.	51 ±13.3	50 ±12.7	T (32) = 0.177, p = 0.971	45 ±15.7	45 ±13.3	T (108) = -0.122, p = 0.137
Sex (Female/Male)	26/12	24/14	X^2 (1) = 0.23, p = 0.62	13/2	10/9	X^2 (1) = 4.437, p = **0.035**	39/14	34/23	X^2 (1) = 2.389, p = 0.122
Years of Education	4 (0-16)	4 (0-14)	U = 858.5, p=0.14	8 (0-25)	5 (0-16)	U = 185.5, p=0.137	4.5 (0-25)	4 (0-16)	U = 1.830, p=0.053
Epilepsy onset	15 (0-50)	8 (0-32)	U = 967.0, **p=0.01**	-	-		-	-	
Last seizure on intervention week	5	8	X^2 (1)=0.83, p=0.36	-	-		-	-	
Seizures per month	0.55 (0-30)	1.5 (0-105)	U = 594.5, p=0.16	-	-		-	-	
Controlled epilepsy	29	29	X^2 (1)=0.0, p=1.0						
Therapeutic regimen			X^2 (1)=1.645, **p=0.02**.	-	-		-	-	
Mono	13(34%)	29(76%)							
Poli	25(66%)	9(24%)							
Withdrawn	-	-							
Ocupation			$X^2(2)$=4.35, p=0.11			$X^2(2)$=2.21, p=0.33			$X^2(2)$=5.17], p=0.075
Employed	7	7		2	6		9	13	
Unemployed	16	8		9	7		25	15	
Others (students, retired, pensioners, housewifes)	15	23		4	6		19	29	

In Table 2, in regard to the self-reported emotional profile (Rational, Intuitive or Emotive), there was no difference between control and intervention when analyzed only in the patient group [$X^2(2) = 0.99$, $p = 0.60$] and in the caregiver group [X^2 (2) = 1.75, $p = 0.41$], as well as no difference for the total population [X^2 (2) = 0.06, $p = 0.96$] when comparing intervention and control.

Table 2. Self-reported emotional profile and emotions chosen to work on during procedures of patients and caregivers, Campinas, 2019.

	Patients			**Caregivers**			**Total**		
Sef-reported emotional profile	Intervention (n=38)	Control (n=38)	$X^2(2)$=0.99, p=0.60	Intervention (n=15)	Control (n=19)	$X^2(2)$=1.75, p=0.41	Intervention (n=53)	Control (n=57)	$X^2(2)$=0.06, p=0.96
Rational	15 (39%)	18 (47%)		10 (67%)	15 (79%)		28 (53%)	30 (53%)	
Intuitive	9 (24%)	10 (26%)		2 (13%)	3 (16%)		12 (23%)	12 (21%)	
Emotive	14 (37%)	10 (26%)		3 (20%)	1 (5%)		13 (25%)	15 (26%)	
Emotions									
Anger	12 (31.6%)	9 (24%)		1 (6.7%)	1 (5.3%)		13 (25%)	10 (18%)	
Concern	8 (21%)	9 (24%)		6 (40%)	8 (42.1%)		14 (26%)	17 (30%)	
Sadness	4 (10.5%)	9 (24%)		-	3 (15.8%)		4 (8%)	12 (21%)	
Compassion	3 (7.9%)	2 (5.2%)		2 (13.3%)	2 (10.5%)		5 (9%)	4 (7%)	
Phobia	3 (7.9%)	1 (2.6%)		2 (13.3%)	-		5 (9%)	1 (2%)	
Comprehension	2 (5.3%)	3 (7.9%)		0 (0%)	1 (5.3%)		2 (4%)	4 (7%)	
Peace	2 (5.3%)	2 (5.3%)		2 (13.3%)	1 (5.3%)		4 (8%)	3 (5%)	
Joy	2 (5.3%)	1 (2.6%)		1 (6.7%)	1 (5.3%)		3 (6%)	2 (4%)	
Did not choose	1 (2.6%)	-		1 (6.7%)	1 (5.3%)		2 (4%)	1 (2%)	
Gratitude	1 (2.6%)	-		-	1 (5.3%)		1 (2%)	1 (2%)	
Euphoria	-	2 (5.3%)		-	-		-	2 (4%)	
Classification of Emotions			$X^2(2)$=0.05, p=0.97			$X^2(2)$=1.380, p=0.502			$X^2(2)$=0.685, p=0.710
Negative	27	30		9	12		36	42	
Positive	10	8		5	6		15	14	
Did not choose	1	-		1	1		2	1	

In Table 2, in regard to the emotions chosen to this intervention, we noticed a prevalence of emotions related to anger, concern, and sadness, with a prevalence of negative over positive emotions, which did not bear a significant difference when comparing groups. There is no significant difference between intervention and control groups for patients [X^2 (2) = 0.05, p = 0.97] and for caregivers [X^2 (2) = 1.38 (2), p = 0.50], as well as no difference for the general population [X^2 (2) = 0.68, p = 0.71]. There is no difference between patients and caregivers either [X^2 (2) = 3.04, p = 0.21].

We also performed two different analysis, which will be described in the following items: i) Perception of changes after 5 min of procedure; ii) Pre and post-procedure Likert scale comparison between control and intervention and between patients and participants.

Outcome Measures

i) Perception of changes after 5 min of procedure

Five minutes after the procedure began, participants from both groups (control and intervention) were asked "How are you feeling?" and the researcher registered as they reported physical and emotional changes.

We classified their responses in categories, as “Yes” or “No” for referral of changes and compared using the Chi-Square test. We found a significant difference in the distribution of presence or absence of comments when comparing intervention and control [X^2 (1) = 11.97, p <0.001]. There is also a difference in the patient and caregiver groups for intervention vs. control as follows: caregivers X^2 (1) = 7.43, p = 0.008; patients X^2 (1) = 5.32, p = 0.01. See figure 4.

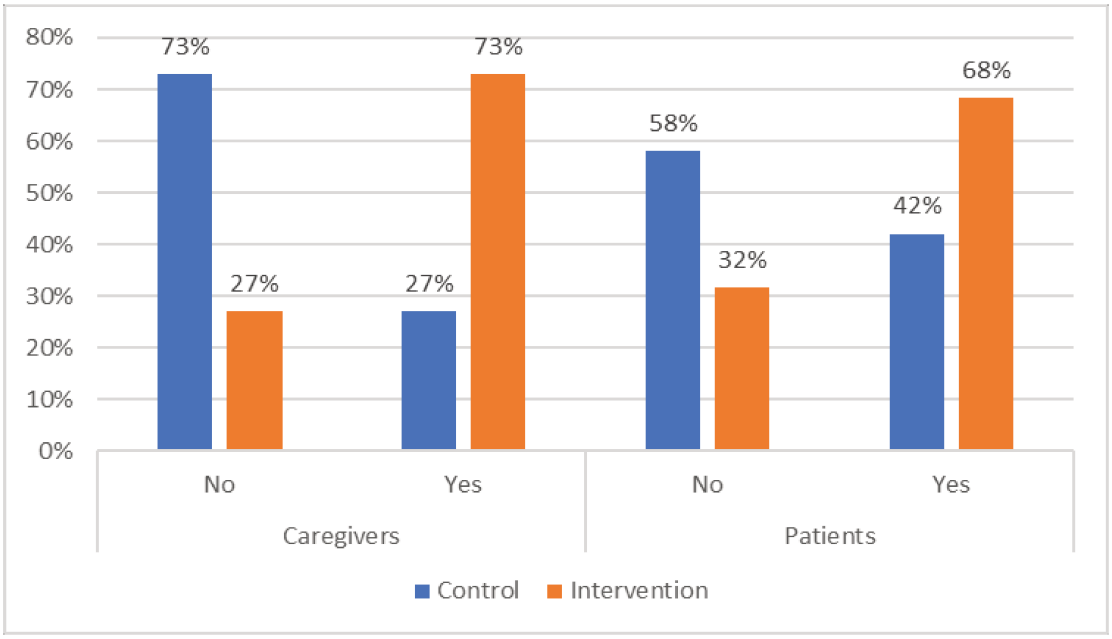

Fig. 4. Frequency of changes reported after intervention according to groups studied.

For participants who perceived changes after intervention, these include feelings of sleep and relaxation, and mind changes refer to positive or negative thoughts, feelings and anxiety, peace, happiness. In table 3, qualitative description was categorized as body or mind changes. In the group of intervention, a caregiver reported

remembering the feeling of fear caused by an accident, and a patient reported feeling levintating and that he "went back to past". Complete data is available in complementary materials.

Table 3 – Body and Mind Changes after 5 minutes of procedure.

	Body Changes	Mind changes	Total
Caregiver Control	Relaxation (1)	Good thoughts (1), impacient, treatment was interrupted (1).	3
Caregiver Intervention	Asleep (5) or slept (1), Felt well (1), Relaxation (2), Slowed breathing (1).	Memory of the fear caused by an accident (1).	11
Patient Control	Asleep (2), Headache (1), Relaxation (2), Slept (3).	Anxious and impatient (1), Peace (1), Reduced anxiety (1).	11
Patient Intervention	Asleep (1), Felt well (1), Happier (1), More anxious (1), Relaxation (7), Slept (10), Slowed breathing (1).	Still concerned (1), Calmer (1), Concerns are gone (1), Feels levitating and went back to past (1).	26

After this question, the intervention group started the mandala of the chosen emotion, with the orientation of "focus on your chosen emotion", whereas the control group maintained the same status of lying down, relaxing and paying attention to the breath.

ii) Pre and pos-procedure Likert scale comparison between control and intervention and between patients and participants

There was a significant effect of the procedure performed [$F_{1,106}$= 27.94, $p < 0.001$]. This effect does not depend on intervention or control but caregivers reported higher values in the Likert Scale both before and after the procedure compared to patients [$F_{1,106}$= 7.789, p= 0.006]. There was no moment of evaluation * patient / caregiver interaction.

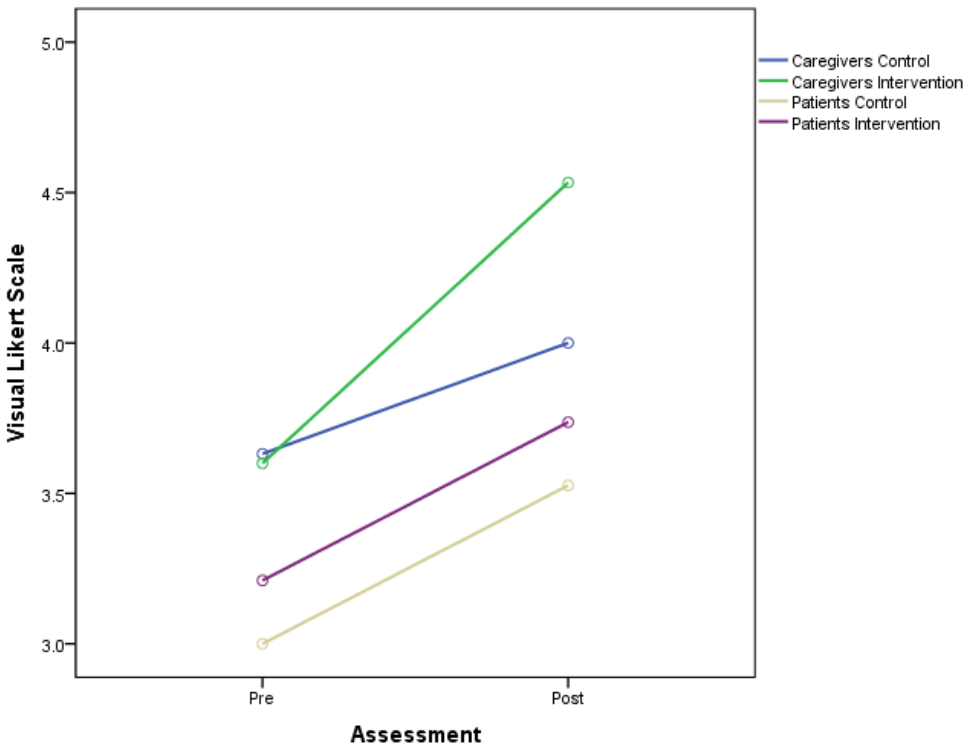

Fig. 5. Pre and post-procedure assessment for Likert scale comparison between groups.

After the procedure, researchers asked whether participants experienced body changes, retrieval of memories, retrieval of specific images, and observations regarding the procedure. Physical changes described as “more relaxed, peaceful and light”, “sleeping” and “anxious”.

Table 4 – Body Changes for each group after procedures.

	Negative change	**Positive change**
Caregiver Control	-	asleep (1), comprehension (1), lighter (1), pain relieve (1), positive thought (1), relaxation (3) warmer (1), tremor (1).
Caregiver Intervention	felt cold (2), anxiety (1), heaviness over the abdomen (1), noise outside disturbed (1), panic (1), tremor (1).	breathing improvement (1), felt well (1), lighter (2), relaxation (1).
Patient Control	anxiety (1), cried (1), drowsiness (1), felt bad, started to roll (1), problems (1), tremor in left hemicorpo (1)	asleep (3), breathing improvement (1), calmer (2), headache (1), lighter (2), relaxation (5)
Patient Intervention	angry (1), back pain (1), pain in a side of the body (1), pulse in temples (1), tickling (1)	asleep (5), breathing improvement (1), dizziness stopped (1), left hand relaxed and head pulled (1), levitating (1), lighter (7), mind alignment (1), relaxation (2)

When questioned about retrieval of memories, participants referred about recall of childhood-related moments and clinical events (medical appointments, seizures, and surgery).

Table 5 – Memories for each group after procedures.

	Person	**Situation**
Caregiver Intervention	ex-husband (1), he recalled the episode in which he fell into the childhood pool and was revived by family members (1), people who lost (by death) (1), when I was studying (1).	accidents (1), performing charity care (1).
Caregiver Control	-	-
Patient Intervention	children (1), daughter (1), deceased parents (1), family (3).	disgust that children caused (1), high school (1), hometown (1), memories about the past (1), of seizures (1), things that hurt in the past, that brought sadness (1), when judge said that he was okay, even though he was not (1), wife who passed away this year (1).
Patient Control	childhood (1), deceased father (1), deceased wife (1), disgust that children caused (1), father's care (1), mother and daughter at home (1), of drug-dependent child (1), past, people (1), the good moments that I lived with my brother (1).	bad thoughts related to epilepsy (1), cause of problems (1), dreams of things he did (1), epilepsy and hope (1), recalled the episode in which he fell into the childhood pool and was revived by family members (1), when I was studying (1).

Retrieval of specific images also brought moments related to memories of childhood, family members and other situations.

Table 6 – Retrieval of images for each group after procedures.

	Caregivers	**Patients**
Control	brother (1), speech and expression when a person has spoken bad words to him (1), wife (1).	childhood (1), children (1), deceased family members (2), deceased father smiling to her (1), deceased parents said that they wanted the family together (1), difficulties (1), falls suffered (1), parents, grandparents (1), sadness (1), sports (1), together with a beloved one (1).
Intervention	accident (1), deceased parents (1), ex-husband (1), green and blue clouds (1), home (1), image of Our Lady (1).	a coleague (1), childhood (1), children playing (1), daughter playing (1), during a seizure, calling his dad (1), Jesus (1), misunderstanding (1), of deaths, and things that upset him (1), things that he had to do (1), When I woke up from the surgery performed in 2014, I saw the doctor's image (1).

We also opened for further observations from participants, when they reported treatment-related concerns, that they felt better, or felt discomfort, or focused only in daily thoughts.

Discussion

A number of challenges exist in treating patients with epilepsy (Ekinci et al, 2009). This is particularly true when associated with co morbidities (Keezer et al, 2016),

when seizures are difficult to control and medication regimens are more complex. Some pharmaceutical options may provide assistance with both seizures and emotional distress, but care is needed when considering such treatment approaches.

Integration of other professionals into the care of patients is necessary when cases are complicated and risk factors are high. Diagnose of emotional distress and regular monitoring of symptoms can help prevent serious problems that can negatively affect children and adolescents in everyday life. Collaboration between disciplines offers the best hope for early identification and treatment of these conditions. Nevertheless, there are constraints in relation to the wide applicability of these techniques: time-consuming, require a long training, constant supervision of instructors, physical and cognitive limitations, high cost.

When analyzing the literature on integrative practices, there is evidence of growing scientific support and acceptance by patients, caregivers, professionals and researchers. Techniques of meditation and self-knowledge can play an important role in therapeutic planning, especially in disease prevention and promotion of well-being. However, there are still gaps in the knowledge, due to small samples and methodological flaws (Roddis & Tanner, 2018). At this point, this research plays a role in contributing to the knowledge construction.

This study reports a significant effect of the procedure performed on self-perceived emotional status for both patients and caregivers, conveyed in a Likert scale that ranges from 1-Very bad to 5-Very good, which does not depend on intervention or control. In other words, a procedure that involves relaxation and paying attention to the breath, with or without Mandalas of Emotions, may induce an improvement in self-perceived emotional status. In parallel, studies on yoga, meditation, music, exercise of spirituality and spiritism show that they can be a positive coping strategy to support the traditional therapy of patients with epilepsy and other neurological disorders.

In relation to yoga, a literature review by Roddis & Tanner (2018) selected only two studies, which are limited due to small samples in randomized control trial and methodological flaws, leading to difficulties in drawing clear conclusions. The first study by Lundgren et al. (2008) found no significant difference when comparing number of seizures experienced by volunteers undertaking yoga and those undergoing Acceptance and Commitment Therapy. The yoga group showed significant enhancement in their quality of life when applying the Satisfaction with Life Scale. The second study, by Panjwani et al. (1996), presented conflicting results. When using ANOVA, there was no statistically significant difference those performing yoga, those praticing exercises that mimic yoga, and those without intervention. Yet, a significant difference was found when using a t-test: between the yoga group and the no intervention group, in relation to the number of seizures and length of seizure.

Therefore, Roddis & Tanner (2018) conclude that in the treatment of refractory epilepsy there is little evidence to show that yoga as a unique intervention may significantly improve symptoms. They argue that other studies with the concomitant use of yoga in the treatment of chronic diseases such as heart disease, stroke and chronic obstructive pulmonary disease (Desveaux et al., 2015) present a potential reduction in rates of anxiety and depression. Greater levels of relaxation may have positive impact on seizure frequency (Haut et al., 2018).

In particular, a type of contemplative practice, meditation, has attracted great attention from both psychologists and neuroscientists in the last two decades due to a growing appreciation of its ability to affect cognition, emotion and decision making. In general, meditation is defined as a wide variety of practices designed to cultivate

emotional balance and psychological well-being, including relaxation, observation of one's inner or outer experiences, and intentional self-regulation of attention (Van Dam et al, 2018).

There are many forms of meditation practice, such as mindfulness, transcendental meditation, Buddhist meditation, among others. Mindfulness refers to a wide range of practices based on promoting a state of non-judgmental and non-reactive awareness that can enhance its ability to modify automatic behaviours in long term (Sun et al., 2015).

Mindfulness interventions have become increasingly popular in contemporary psychology. Other closely related meditation practices include loving-kindness (LKM) and compassionate meditation (CM). Preliminary results from a study of 93 patients showed that, after performing CM exercises, neuroendocrine markers were reduced for stress caused by distress and also improved immune response. A neuroimaging study revealed that the association of LKM and CM can increase the activation of brain areas involved with emotional processing and empathy (Hofmann et al., 2011). Authors concluded that the combination of two techniques may provide potentially useful strategies for targeting a variety of psychological problems involving interpersonal processes such as anxiety, marital conflict, anger and tensions of caregivers.

One of the limitations in integrative therapy studies is the sample number. In a study to evaluate the quality and results of randomized controlled trials (RCTs) of Biofield therapies, researchers concluded that, despite the significant and statistically beneficial results, the nature of the pilot study does not provide a sufficient sample (Hammerschlag et al., 2014). Thus, it is necessary to continue the development of projects to obtain more consistent results on integrative therapies focused on meditation and emotional balance.

Nonetheless, the challenge in applying such techniques relies in its adhesion and sustainability. If the chosen therapy (e.g., meditation) requires complex training and follow-up, it reduces the likelihood of support and autonomy to practice it on a daily basis. Ideally, initial training should provide concepts in a simple way, allowing them to be easily and effectively introduced in the routine, and to promote establishment groups to share experiences and promote mutual support.

ME differs from yoga, meditation and mindfulness. Mindfulness exercises that the mind must remain in contemplation of not judging, free of thoughts, letting it flow, and focusing on the present. On the other hand, ME mediates the recognition and to work on emotions through a nine steps process: identify, receive, accept, access, revisit, understand, reflect, resignify and release. Awareness of one's own emotions opens the possibility for acquiring a new vision for problem solving and decision making.

Another important outcome is that caregivers reported higher values in the Likert Scale on self-perceived emotional status both before and after the procedure compared to patients. Our hypothesis is that this result may be related to the burden of epilepsy, which includes medication side-effects, such as poor concentration and sleep deprivation, and may decrease the attention and self-analysis demanded by this method. Also, cultural background may influence this outcome. Years of education and openness to alternative medicine may alter comprehension and acceptance of this technique. Since the procedure, control or intervention, brought a significant difference, one may argue that the simple fact of giving a special attention to these participants could have, by itself, caused a feeling of improvement. There were also participants that reacted in a negative way, which might be related to a resistance to integrative and/or complementary approach or to talk about their emotions, despite giving the consent and showing interest in the research.

Our study has several limitations that need to be acknowledged. Differences in sex distribution in caregivers, with a greater number of females in the intervention group for caregivers may have influenced the perception of the Mandalas of Emotions. Also, we did not investigate the religion of our research participants, which may have caused a bias. Research procedures were performed before the clinical appointment with the neurologist, without a previous invitation. Thus, this might have caused an anxiety on the participant related to whether he would miss his appointment, despite reassuring him of the contrary, and having the support of the Outpatients' clinical staff to prevent this from happening. Nevertheless, noise and talks in the corridor might have altered the performance in the requested tasks, that involved concentration efforts, such as "relax and pay attention to your breath" or "focus on your chosen emotion".

In our study, while relaxing with these stones, patients and caregivers reported the following sensations: tingling, heat, pulsation or awakening of certain memories. According to Ling, application of ME aims to bring a new awareness and attitude towards life situations. Variations of feelings and emotions are part of the human universe. According to the TCM, emotions express the relation with the body and the mind and provide a bridge to access the abilities of self-healing (Ling, 2013). Even though the mechanism is still unknown, changes in emotional aspects as reported by volunteers of this research corresponded to changes in the body.

Conclusion

Although epilepsy is considered a neurological condition, the consequences for the patient are extended to behavior, psychosocial adjustment and quality of life. When facing internal conflicts, patients may develop a blockage in self-ability, understanding of feelings and social withdrawal, implying directly in the way they express their emotions, desires and opinions. Thus, recognition and coping of the patient's and family's emotions can collaborate to establish an effective understanding of the condition and improve life quality.

This randomized control trial study showed a significant difference between control and intervention subjects only 5 minutes after procedure. Nevertheless, Mandala of Emotions presents a therapeutic potential as an easy-to-apply method to facilitate the perception of feelings and may help self-solving internal conflict and ways to cope with epilepsy. The Mandalas of Emotions is not a method for relaxation, but a method to elucidate an emotion, enabling the person to consciously analyze and understand its impacts in his/her life. In order to assess this potential, further studies may evaluate long-term effectiveness of Mandalas of Emotions as an integrative practice to improve quality of life.

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Complementary Materials

Qualitative results

i) Perception of changes after 5 min of procedure

Table 3. Description of changes per procedure and group, Campinas, 2019.

Group	Procedure	Classification	Description
Patient	Intervention	body changes	feels as if levitating, went back to past
Patient	Intervention	body changes	more relaxed
Patient	Intervention	body changes	slept and dreamt
Patient	Intervention	body changes	more relaxed, enjoyed the session
Patient	Intervention	body changes	breathing was slower, but referred feeling more anxious
Patient	Intervention	body changes	I was able to control my breathing, reduce my heart rate and relax my body
Patient	Intervention	body changes	relaxed
Patient	Intervention	body changes	relaxed
Patient	Intervention	body changes	almost slept, relaxed, about anxiety I feel calm
Patient	Intervention	body changes	slept
Patient	Intervention	body changes	feeling relaxed
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	felt lighter
Patient	Intervention	body changes	asleep
Patient	Intervention	body changes	breathing became slower, and hunger sensation reduced

Patient	Intervention	body changes	feels very well, I want to do that at home
Patient	Intervention	body changes	feels calmer, I was able to forget about problems
Patient	Intervention	body changes	slept
Patient	Intervention	body changes	feels nice and asleep, wishes to have more sessions
Patient	Intervention	mind changes	there were several thoughts concerning her, and they are all gone
Patient	Intervention	mind changes	felt happier, sadness was gone
Patient	Intervention	mind changes	always feels concerned
Caregiver	Intervention	body changes	breathing was fast and came back to normal
Caregiver	Intervention	body changes	heart sped up, feels well
Caregiver	Intervention	body changes	slept
Caregiver	Intervention	body changes	asleep
Caregiver	Intervention	body changes	sudosis feeling in hands, but quiet and relaxed, asleep
Caregiver	Intervention	body changes	asleep
Caregiver	Intervention	body changes	asleep
Caregiver	Intervention	body changes	asleep
Caregiver	Intervention	body changes	relaxed
Caregiver	Intervention	mind changes	the thought of the fear caused by the accident
Caregiver	Intervention	mind changes	relaxed, feels courage to face fears
Patient	Control	body changes	asleep
Patient	Control	body changes	relaxed body
Patient	Control	body changes	rested
Patient	Control	body changes	slept
Patient	Control	body changes	headache
Patient	Control	body changes	slept
Patient	Control	body changes	slept
Patient	Control	body changes	asleep
Patient	Control	mind changes	felt peace, mind travelled
Patient	Control	mind changes	anxiety decreased
Patient	Control	mind changes	anxious and impacient
Caregiver	Control	body changes	relaxed
Caregiver	Control	mind changes	impacient, treatment was interrupted
Caregiver	Control	mind changes	good thoughts

ii) Pre and pos-procedure Likert scale comparison between control and intervention and between patients and participants

Table 4. Description of body changes per procedure and group, Campinas, 2019.

Group	**Procedure**	**Classification**	**Description of body change**
Patient	Intervention	positive change	it felt like I was levitating
Patient	Intervention	positive change	sleepiness, light body
Patient	Intervention	positive change	lighter
Patient	Intervention	positive change	lighter
Patient	Intervention	positive change	lighter
Patient	Intervention	positive change	normal relaxation, breath control
Patient	Intervention	positive change	don't feel dizzy anymore, I felt before entering
Patient	Intervention	positive change	sleep (body pain is gone)
Patient	Intervention	positive change	lighter breathing, feeling of tranquility
Patient	Intervention	positive change	relaxation and physical well being
Patient	Intervention	positive change	extreme lightness, almost levitating
Patient	Intervention	positive change	sleepiness and Light Body
Patient	Intervention	positive change	mind alignment
Patient	Intervention	positive change	left hand relaxed and head pulled
Patient	Intervention	positive change	lighter
Patient	Intervention	positive change	start: fluctuation. End: yawning without feeling sleepy
Patient	Intervention	positive change	much lighter, felt comfortable
Patient	Intervention	positive change	sleep

Patient	Intervention	positive change	slept, tingled in his abdomen, arms and legs - a good feeling
Patient	Intervention	negative change	knee was tickling
Patient	Intervention	negative change	pain in a side of the body
Patient	Intervention	negative change	angry, kept waiting
Patient	Intervention	negative change	back pain
Patient	Intervention	negative change	hunger is gone, pulse in temples
Patient	Control	positive change	calmer
Patient	Control	positive change	rest
Patient	Control	positive change	lightness
Patient	Control	positive change	sleep
Patient	Control	positive change	breathing improvement
Patient	Control	positive change	relaxed his backs
Patient	Control	positive change	drowsiness and relaxation
Patient	Control	positive change	sleep
Patient	Control	positive change	became calmer
Patient	Control	positive change	discomfort, headache
Patient	Control	positive change	rested the body
Patient	Control	positive change	lighter body
Patient	Control	positive change	massage sensation
Patient	Control	positive change	sleep
Patient	Control	negative change	only drowsiness
Patient	Control	negative change	cried
Patient	Control	negative change	problems
Patient	Control	negative change	anxious
Patient	Control	negative change	tremor in left hemicorpo
Patient	Control	negative change	felt bad, started to roll
Caregiver	Intervention	negative change	sweat on hands and bobbing
Caregiver	Intervention	positive change	faster breathing at first, then normalized
Caregiver	Intervention	positive change	anxious
Caregiver	Intervention	positive change	light head and body
Caregiver	Intervention	positive change	lightness
Caregiver	Intervention	positive change	felt very good
Caregiver	Intervention	positive change	wind and cold feet
Caregiver	Intervention	positive change	relaxed
Caregiver	Intervention	negative change	panic
Caregiver	Intervention	negative change	at first it felt cold, it felt different
Caregiver	Intervention	negative change	heaviness over the abdomen
Caregiver	Intervention	negative change	tried to hear the breath inside but the outside noise disturbed
Caregiver	Control	positive change	lightness
Caregiver	Control	positive change	felt his whole body heat up a little
Caregiver	Control	positive change	comprehension
Caregiver	Control	positive change	the pain passed
Caregiver	Control	positive change	muscle relaxation
Caregiver	Control	positive change	accommodated / relaxed
Caregiver	Control	positive change	positive thoughts of change
Caregiver	Control	positive change	relaxation
Caregiver	Control	positive change	sleep

When questioned about retrieval of memories, participants referred about recall of childhood-related moments and clinical events (medical appointments, seizures, and surgery). See Table 5.

Table 5. Description of retrieval of memories per procedure and group, Campinas, 2019.

Group	Procedure	Classification of memories	Description of memories
Patient	Intervention	Person	deceased parents
Patient	Intervention	Person	family

Patient	Intervention	Person	family
Patient	Intervention	Person	family
Patient	Intervention	Person	children
Patient	Intervention	Person	daughter
Patient	Intervention	Situation	memories about the past
Patient	Intervention	Situation	things that hurt in the past, that brought sadness
Patient	Intervention	Situation	wife who passed away this year
Patient	Intervention	Situation	disgust that children caused
Patient	Intervention	Situation	hometown
Patient	Intervention	Situation	high school
Patient	Intervention	Situation	when judge said that he was okay, even though he was not
Patient	Intervention	Situation	of seizures
Patient	Control	Person	childhood
Patient	Control	Person	mother and daughter at home
Patient	Control	Person	father's care
Patient	Control	Person	deceased father
Patient	Control	Person	the good moments that I lived with my brother
Patient	Control	Person	of drug-dependent child
Patient	Control	Person	past, people
Patient	Control	Person	disgust that children caused
Patient	Control	Person	deceased wife
Patient	Control	Situation	bad thoughts related to epilepsy
Patient	Control	Situation	epilepsy and hope
Patient	Control	Situation	cause of problems
Patient	Control	Situation	dreams of things he did
Patient	Control	Situation	when I was studying
Patient	Control	Situation	recalled the episode in which he fell into the childhood pool and was revived by family members
Caregiver	Intervention	Person	ex-husband
Caregiver	Intervention	Person	when I was studying
Caregiver	Intervention	Person	he recalled the episode in which he fell into the childhood pool and was revived by family members.
Caregiver	Intervention	Person	people who lost (by death)
Caregiver	Intervention	Situation	accidents
Caregiver	Intervention	Situation	performing charity care

Retrieval of specific images also brought moments related to memories of childhood, family members and other situations. See Table 6.

Table 6. Description of retrieval of specific images per procedure and group, Campinas, 2019.

Group	Procedure	Topic	Image description
Patients	Intervention	Family	daughter playing
Patients	Intervention	Family	children playing
Patients	Intervention	Others	childhood
Patients	Intervention	Others	a colleague
Patients	Intervention	Others	of deaths, and things that upset him
Patients	Intervention	Others	things that he had to do
Patients	Intervention	Others	misunderstanding
Patients	Intervention	Others	When I woke up from the surgery performed in 2014, I saw the doctor's image
Patients	Intervention	Others	Jesus
Patients	Intervention	Others	during a seizure, calling his dad
Patients	Control	Family	parents, grandparents, Fod
Patients	Control	Family	deceased father smiling to her
Patients	Control	Family	deceased family members
Patients	Control	Family	together with a beloved one
Patients	Control	Family	deceased family members

Patients	Control	Family	children
Patients	Control	Family	deceased parents said that they wanted the family together
Patients	Control	Others	childhood
Patients	Control	Others	difficulties
Patients	Control	Others	falls suffered
Patients	Control	Others	sadness
Patients	Control	Others	sports
Caregivers	Intervention	Family	ex-husband
Caregivers	Intervention	Family	deceased parents
Caregivers	Intervention	Others	home
Caregivers	Intervention	Others	accident
Caregivers	Intervention	Others	green and blue clouds
Caregivers	Intervention	Others	image of Our Lady
Caregivers	Control	Family	brother
Caregivers	Control	Family	wife
Caregivers	Control	Family	speech and expression when a person has spoken bad words to him

We also opened for further observations from participants, when they reported treatment-related concerns, that they felt better, or felt discomfort, or focused only in daily thoughts. See Table 7.

Table 7. Description of observations per procedure and group, Campinas, 2019.

Group	**Procedure**	**Classification**	**Observation**
Patient	Intervention	Treatment-related	is in search of understanding
Patient	Intervention	Treatment-related	patient reports that during relaxation he has the idea of seeking a psychotherapist
Patient	Intervention	Felt better	slept
Patient	Intervention	Felt better	felt great, it is fantastic
Patient	Intervention	Felt better	felt very well, never felt like this before
Patient	Intervention	Felt better	She couldn't let her thoughts flow because she is so worried about her health problems, but she clearly felt that she was more confident and stronger in dealing with them.
Patient	Intervention	Felt better	Observed little improvement
Patient	Intervention	Felt better	felt happiness and the presence of God
Patient	Intervention	Felt better	suggests that this kind of intervention be done in the working environment of people
Patient	Intervention	Discomfort	thinking about the daughter caused discourage
Patient	Control	Treatment-related	thought about quitting treatment
Patient	Control	Treatment-related	thought about solving health issues
Patient	Control	Treatment-related	thought about a solution for the seizure
Patient	Control	Discomfort	felt discomfort about staying indoors
Caregiver	Intervention	Felt better	enjoyed the method, since it transmitted tranquility
Caregiver	Intervention	Felt better	reported feeling slightly better than before
Caregiver	Intervention	Discomfort	questioned whether this procedure was against religious principles
Caregiver	Control	Daily thoughts	focused in organizing my tasks for the day
Caregiver	Control	Daily thoughts	worried about the sister, who was waiting

DISCUSSÃO GERAL

A presente tese reúne estudos sobre as emoções no contexto de uma doença crônica neurológica, a epilepsia; a expressão artística dessas emoções como forma de difusão do conhecimento científico; a proposta de um método, as Mandalas das Emoções (MEs), para facilitar o reconhecimento e o enfrentamento das emoções, na perspectiva de um estudo randomizado caso controle. Também apresenta, nos anexos, um estudo de caso com a aplicação das Mandalas das Emoções a um paciente com câncer, assim como descreve uma contribuição para o método das MEs com a criação e validação de processos sonoros para fins terapêuticos, e um estudo longitudinal sobre a aplicação das Mandalas das Emoções.

Este método, as Mandalas das Emoções, posiciona-se como uma possibilidade para ajudar o indivíduo a enfrentar as emoções, aliviar o sofrimento, e proporcionar um bem-estar emocional[44]. O relato de caso (anexo I) indica também uma maior facilidade de acesso pelo indivíduo ao seu próprio conteúdo emocional e às lembranças, despertando a vontade ou capacidade de refletir. A estes, confere-se uma nova interpretação sobre a relação com o mundo e consigo, ampliando a consciência tanto sobre o âmbito ao qual se insere quanto sobre si mesmo[44].

Considerando-se o contexto da epilepsia, conforme descrito no primeiro capítulo, uma doença crônica com importante impacto psicossocial, a vulnerabilidade aos agravos em saúde mental intensifica-se devido à estigmatização, falta de consciência e à lacuna nos recursos acessíveis para pacientes com epilepsia[50]. Além disso, pacientes com epilepsia podem apresentar déficits relacionados à cognição social, conforme apontam estudos por Jiang et al[51] e Realmuto et al[52]; e ansiedade e depressão em crianças[53].

No estudo descrito no capítulo 1, o compartilhamento de histórias de vida permitiu aprendizado sobre a epilepsia e novas possibilidades de estratégias de enfrentamento da doença, criando potencial para o desenvolvimento pessoal.

O estudo descrito no segundo capítulo contribui para reduzir a estigmatização ao retratar as emoções da pessoa com epilepsia por meio de uma apresentação artística. Esta teve por intuito provocar emoções na plateia, transmitindo uma percepção sensorial sobre o contexto psicossocial ao qual a pessoa com epilepsia se insere e, dessa maneira, favorecendo a empatia com relação à pessoa com epilepsia.

Por fim, o estudo randomizado caso controle apresentou uma diferença significativa na percepção de alterações após 5 minutos do início do procedimento; com maior efeito no grupo intervenção e nos cuidadores em comparação aos pacientes.

É importante lembrar que na Medicina Tradicional Chinesa o bem-estar é um estado de harmonia entre emoção e corpo físico. Segundo a MTC, ao reestruturar o lado emocional, o organismo se encarrega de ir ao encontro da resposta. Outras metodologias apontam que o uso de práticas integrativas, como a meditação, tem efeitos benéficos. Nesse sentido, a estratégia de reconhecer e lidar com as emoções está diretamente relacionada com o construto teórico da inteligência emocional. Por esse motivo, a próxima seção discute sobre esse conceito, de maneira a relacionar com o método das Mandalas.

A inteligência emocional

O processo de reconhecimento e entendimento das emoções faz parte do construto teórico da Inteligência Emocional. Suas raízes remontam o trabalho de Thorndike, de 1920[54], o qual descrevia a habilidade de compreender, gerenciar, e interagir de forma sábia com outros. A teoria de Gardner[55] descreve sobre a inteligência intra e interpessoal, a qual incluem a habilidade em compreender intenções, motivações e desejos de si e do outro, respectivamente.

A partir desses conceitos, vários autores utilizaram o termo inteligência emocional (IE)[56-58], definido em dois modelos: um baseado em medir habilidades de desempenho e outro, nas características autorreferidas[59,60]. Apesar da discordância entre os modelos de mensuração, existe um consenso

de que o construto da IE envolve pelo menos dois domínios amplos: reconhecer/entender emoções e adaptar/gerar/regular emoções[61,62].

Em essência, existem dois pontos de vista sobre Inteligência Emocional[63]: alguns argumentam que a inteligência emocional inclui tudo o que não é medido pelo QI, mas está relacionado ao sucesso[64,65]; outros defendem um modelo de capacidade de inteligência emocional, que mede a capacidade de perceber e entender informações emocionais[66].

De acordo com Salovey & Mayer[67], inteligência emocional corresponde ao subconjunto da inteligência social, relacionado à capacidade de identificar os próprios sentimentos e sentimentos dos outros, e usar essas informações para orientar o pensamento e as ações. Assim, esse modelo define a IE como a capacidade de perceber, entender, gerenciar e usar emoções para facilitar pensamento, medido por um questionário baseado em habilidade.

Os autores Salovey&Meyer[67] desenvolveram uma ferramenta nomeada como Mood Meter, uma figura em plano cartesiano, a qual possibilita a discriminação das emoções com relação ao nível de energia (eixo y) e o nível de satisfação (eixo x). A técnica do Mood Meter, desenvolvida por Salovey&Meyer (1990) utiliza as seguintes perguntas:

1. Qual sua posição no Mood Meter?
2. O que o levou a se sentir dessa forma?
3. Qual palavra melhor descreve seu sentimento atual?
4. Como você está expressando esse sentimento?
5. Considerando o que você sente, qual estratégia você usa para regular suas emoções?

Essa figura aplica o mesmo conceito utilizado no estudo 5, o modelo circumplexo das emoções, proposto por Russell[42]. Da mesma forma, esse modelo descreve as emoções como uma combinação de duas dimensões lineares, que variam quanto ao grau de valência (positiva ou negativa, no eixo x) e excitação (alta ou baixa, no eixo y).

Em 1995, Goleman publicou o livro “Inteligência Emocional” [56]. Neste, o autor aborda o conceito como uma variedade de competências e habilidades, com foco na gestão e no desempenho no trabalho. Dentre essas habilidades,

destacam-se a autoconsciência, autogestão, consciência social e gestão de relacionamento, interligadas e interdependentes.

Em publicação por Bar-On[64], o pesquisador define inteligência emocional como o aspecto que governa nossa habilidade de reconhecer, compreender, controlar e usar as emoções na solução de problemas de natureza pessoal ou interpessoal. O modelo Bar-On[64], que descreve um corte transversal de competências emocionais e sociais inter-relacionadas, habilidades e facilitadores que impactam comportamento inteligente, medido por auto relato dentro de uma abordagem multimodal expansível, incluindo entrevista e avaliação.

Além destes modelos, é importante citar o conceito da Agilidade Emocional, conforme descrito por Susan David, em seu livro de mesmo título[68]. A autora elabora a metáfora do ginasta, referindo-se à capacidade de lidar com as emoções como a habilidade de um ginasta em saltar obstáculos. Ela também introduz o conceito de que existem diferentes (e não tão efetivas) formas de lidar com as emoções, nomeando-as como repressão, quando os sentimentos são ignorados e reprimidos, e ruminação, quando a forma de lidar com o sentimento é fazê-lo voltar à tona diversas vezes, contudo, sem efetivamente compreendê-lo.

Há considerável consenso de que um IE mais alto, se medido em um nível apropriado deve estar associado a um funcionamento social/emocional mais adaptável - e que programas de treinamento projetados para melhorar a IE podem, portanto, oferecer benefícios consideráveis em vários domínios, incluindo satisfação no relacionamento, capacidade de liderança, sucesso na carreira, saúde física/emocional e muitos outros[69-71].

Essa idéia também ganha apoio de anteriores estudos sugerindo que os escores das medidas relacionadas à IE tendem a melhorar com a idade[72,73], bem como com treinamento em outros domínios (por exemplo, aulas de música[74]); isto é, esses resultados são mais consistentes com a ideia que o construto IE se refere a um conjunto de habilidades psicológicas para as quais a experiência pode ser adquirida através de prática/experiência suficientes.

Em estudos com adolescentes, a inteligência emocional fornece competências necessárias para navegar por tempestade e estresse de mudança e transição[75]. Por outro lado, uma incapacidade (percebida) de lidar com tais sentimentos de confusão e dúvida descobriu-se associada a um estilo de identidade que evita a exposição[76]. O que pode importar mais que a inteligência emocional, portanto, são as autopercepções da inteligência emocional, denominadas “Traço Inteligência Emocional” ou “Autoeficácia Emocional” [77]. Essa capacidade de adaptação à mudança pode ter relevância no momento do diagnóstico da epilepsia.

Em revisão de literatura por Baudry et al[78], escores mais altos do Traço Inteligência Emocional ou traço-IE estão associados a uma melhor saúde mental, física e geral em populações clínicas e saudáveis. Isso pode ser explicado por um melhor uso de práticas proativas de saúde de autocuidado, maior recursos de apoio, emoções mais positivas e enfrentamento adaptativo [79]. A saúde mental pode depender mais diretamente das emoções enquanto a saúde física poderia depender mais de hábitos de saúde.

Em estudo por Hajisabbagh[80], pesquisadores comparam a estratégia para lidar com o estresse e a pontuação em escala de inteligência emocional. A maioria dos pacientes com epilepsia usa a estratégia de enfrentamento focada na emoção para lidar com o estresse. Além disso, a média desvio padrão da pontuação total da inteligência emocional no 285,6 ± 39,5, e a maioria (82,2%) apresentou moderada inteligência emocional. O estudo destaca a importância de estratégias que permitam enfrentamento mais eficaz.

As Mandalas das Emoções descendem de uma cultura secular, a Medicina Chinesa, e estabelecem uma ponte com teorias sobre respostas emocionais do Ocidente, para atender uma necessidade tão antiga e complexa quanto os seres humanos: a compreensão de si mesmo e do outro. Evocar, comunicar e compreender emoções são habilidades essenciais para manter o equilíbrio do corpo e da mente.

Na epilepsia, uma doença neurológica comum, os fatores psicológicos e emocionais ainda consistem como barreiras importantes para a socialização e

a qualidade de vida. Esses aspectos não são abordados de forma rotineira, ficando ao encargo de cuidados especializados.

As Mandalas das Emoções, por sua característica não invasiva, fácil e de custo baixo, tornam-se uma alternativa para os pacientes na gestão do autocuidado e autoconhecimento. Seus efeitos são imediatos, tanto físicos quanto ao elicitar emoções. Estudos futuros podem ser desenvolvidos para verificar outros parâmetros clínicos, e aplicar o método como prática integrativa em novos contextos.

CONCLUSÃO

A presente tese propôs o estudo sobre as emoções de pacientes com epilepsia e seus cuidadores e estratégias para sua expressão e enfrentamento.

Por meio do estudo “Dialogando com as emoções”, analisou-se qualitativamente as causas de sofrimento psíquicos no paciente com epilepsia e seus cuidadores por meio do grupo Dialogando com as emoções. O compartilhamento de histórias de vida permitiu aprendizado sobre a epilepsia e novas possibilidades de estratégias de enfrentamento da doença, criando potencial para o desenvolvimento pessoal.

Em segundo lugar, o estudo publicado na Epilepsy & Behavior permitiu traduzir os resultados do estudo anterior para a expressão artística, como uma maneira inovadora de difundir o conhecimento sobre a epilepsia. A apresentação comunicou percepções sobre a epilepsia de forma a criar uma experiência para seu público, disseminar resultados de pesquisa, promover empatia e compaixão.

Por último, com a aplicação de um estudo randomizado caso controle, realizou-se a avalição do efeito agudo das Mandalas das Emoções como uma possibilidade de método para reconhecer as emoções. O estudo randomizado caso controle apresentou uma diferença significativa somente na percepção de alterações após 5 minutos do início do procedimento; com maior efeito no grupo intervenção e nos cuidadores em comparação aos pacientes.

Os estudos supracitados contribuíram com benefícios tanto para a comunidade que atende, ao promover o acesso a um grupo para pacientes e cuidadores e a uma prática integrativa, quanto para a construção de evidências científicas que sustentem sua aplicação.

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ANEXOS

Anexo I. Capítulo publicado em livro: Mandalas of Emotions as Add-on Therapy for Self-Healing and Resolution of Internal Conflicts in Cancer Treatment por Gabriela Salim Spagnol, Li Hui Ling e Li Li Min, publicado no mesmo livro.

Anexo II. Artigo publicado em anais de congresso: A Proposal of Emotion Evocative Sound Compositions for Therapeutic Purposes por Gabriela Salim Spagnol, Li Hui Ling, Li Li Min e Jônatas Manzolli.

Anexo III. Mandalas das emoções para enfrentamento do sofrimento psíquico de pacientes com doenças crônicas e vulneráveis no sistema único de saúde: estudo de caso. Autores: Gabriela Salim Spagnol, Carolinne Yuri Tagami, Isilda Sueli Andreolli Mira de Assumpção, Li Hui Ling, Li Li Min. Apresentado na III Jornada de Práticas Integrativas e Complementares em Saúde: Evidências Científicas, promovida pelo Grupo Estudo das Práticas Integrativas Complementares em Saúde, na Escola de Enfermagem da Universidade de São Paulo, no dia 05 de outubro de 2018, na modalidade Oral.

Anexo IV. Parecer do Comitê de Ética

Anexo V. Autorização para reproduzir os capítulos publicados pela Brill

Anexo VI. Definições da Elsevier para reproduzir capítulo 2.

Anexo VII. Registro no Clinical Trial.

Anexo I. Mandalas of Emotions as Add-on Therapy for Self-Healing and Resolution of Internal Conflicts in Cancer Treatment, publicado no livro "The Patient-Doctor Dynamics

CHAPTER 3

Mandalas of Emotions as Add-on Therapy for Self-Healing and Resolution of Internal Conflicts in Cancer Treatment

Gabriela Salim Spagnol, Li Hui Ling and Li Li Min

1 Cancer Triggers Emotional Conflicts

Cancer remains one of the leading causes of death worldwide.[1] In 2005, approximately 7 million lives were lost to cancer globally, ranking as the second cause of death in many countries, after cardiovascular diseases.[2] According to Ma and Yu (2006),[3] older people are most susceptible to cancer. Along with the population aging, incidence rates will continuously increase in the future, especially in developing countries, with an estimative of up to 15 million new cases in 2020.[4] In low- and middle-income countries, the foreseeable increase in the cancer burden will be even more profound.[5] As developing countries succeed in achieving lifestyles similar to those in advanced economies, they will also face much higher cancer rates, particularly cancers of the breast, colon, prostate and uterus (endometrial carcinoma).[6]

Cancer and its treatment trigger emotional conflicts, which may negatively impact on treatment evolution. During the last decades, the mention of this disease was shrouded by an atmosphere of fear and uncertainty, due to the high rates of death and lack of effective treatments. Even though survival rates have increased, challenges imposed by the treatment, such as hair loss, immunosuppression, associated diseases and physical frailty, bring a great psychological burden to the patient and family. For this reason, add-on therapies

1 Panos Kanavos, "The Rising Burden of Cancer in the Developing World," *Annals of Oncology* 17 (2006): 23.
2 Ibid.
3 Xiaomei Ma and Herbert Yu Ma, "Global Burden of Cancer," *Yale Journal of Biology and Medicine* 79 (2006): 86.
4 Panos Kanavos, "The Rising Burden of Cancer in the Developing World," 25.
5 Frank A. Sloan and Hellen Gelband, *Cancer Control Opportunities in Low- and Middle-Income Countries* (Washington, DC: National Academies Press, 2007), 20–65.
6 Ibid.

 | DOI:10.1163/9789004386563_005

play an important role in improving the ability to cope as well as levels of self-esteem, which are issues that are limited and often neglected.

In this sense, the technique "Dialogue with emotions through mandalas" has been applied in order to promote higher awareness of emotions and coping with the disease. Dr. Ling developed the method called "Dialogue with emotions" with a reference to Traditional Chinese Medicine (TCM), aiming to improve recognition and understanding of emotions, and raising self-awareness in order to deal with internal conflicts.[7]

2 Ecological Harmony through the Eyes of Traditional Chinese Medicine

For over 5000 years, members of the Chinese ancient civilization believed that the human being is equal to a miniature universe that functions the same way as nature with its seasonality. For this reason, human beings are considered microcosms in which movements occur just like the changing of the five seasons: spring, summer, high summer, autumn and winter.

The Traditional Chinese Medicine bases its concepts on these five movements, as well as in the functional rhythm of the body, that symbolizes the integration of cycle of plants with changes of seasons, and which are represented by colours and related to different functional systems of the human body. For instance, upon the arrival of spring, plants sprout green; by summer time, the red colour refers to the heat and higher temperatures; and the height of summer when the earth provides the harvest, is represented by yellow, in a reference to fertility. Fall, in turn, is depicted in white, as the temperature drops, and, finally, winter as black, due to lack of sun light. In relation to the human body, green is related to the functional system of the liver, red to the heart, yellow to spleen and pancreas, white to lungs and black to the kidneys.

The definition of well-being of the TCM comprises not only the absence of physical complaints, but a complete harmony in regard to the physical, emotional and mental spheres. Variations of feelings and emotions are part of the human universe. According to the TCM, emotions express the relation with the body and the mind and provide a bridge to access the abilities of self-healing.[8]

The use of stones with a reference to traditional Chinese medicine is a symbolic way to access the emotional level of the human being, and at the same

7 Li Hui Ling, *Dialogando com as Emoções e Promovendo a Saúde* (Curitiba: Insight, 2013), 5–40.
8 Ibid.

time to cognitively train the abilities related to intuition, creativity and imagination. TCM applies the idea of movement, the art of navigating in a world where every aspect presents two opposite poles, positive and negative, male and female, yin and yang.

3 Translating the Ancient Knowledge

The Mandalas of Emotions applies the Chinese concept of the five movements, five emotions, five colours (green – liver, red – heart, yellow – spleen, white – lungs, black – kidney), Ying/Yang and five directions, providing a composition of stones according to the patient needs. This technique uses five coloured stones the size of a walnut, each of which represents a connection with the universe, according to the five seasons defined by TCM. A relation to the five functional systems (liver, heart, spleen and pancreas, lungs and kidney) is established. These systems work as a network and changing one of the five variables alters the other. Therefore, the Mandalas of Emotions establishes the relation between these five aspects and the emotions, as well as its opposites, as depicted in Figure 3.1.

Depending on the patient needs, one of the five emotions is chosen and stones are placed in a composition, as depicted in Figure 3.2.

The stones are placed around the patient or on his/her abdomen, depending on the self-perceived personality type, according to the classification: 1) intuitive – location: feet; 2) emotive – location: abdomen; 3) rational – location: head.

While relaxing with these stones, patients are guided to connect with their interior, awakening the possibility of self-healing and resilience (see Figure 3.3). According to Ling, this healing corresponds to a new awareness, a new attitude towards life situations. During this treatment, patients report sensations that may include: tingling, heat, pulsation or awakening of certain memories.[9]

The method does not intend to make a diagnosis and treatment of disease (see below a summary of instructions of how to apply mandalas). It is important to remember that in traditional Chinese medicine well-being is a state of harmony between emotion and physical body. By restructuring the emotional aspect, the body will also respond.

How to apply Mandalas of Emotions?

1) Take a deep dive in the five emotions:

- *anger/understanding,*

9 Ibid.

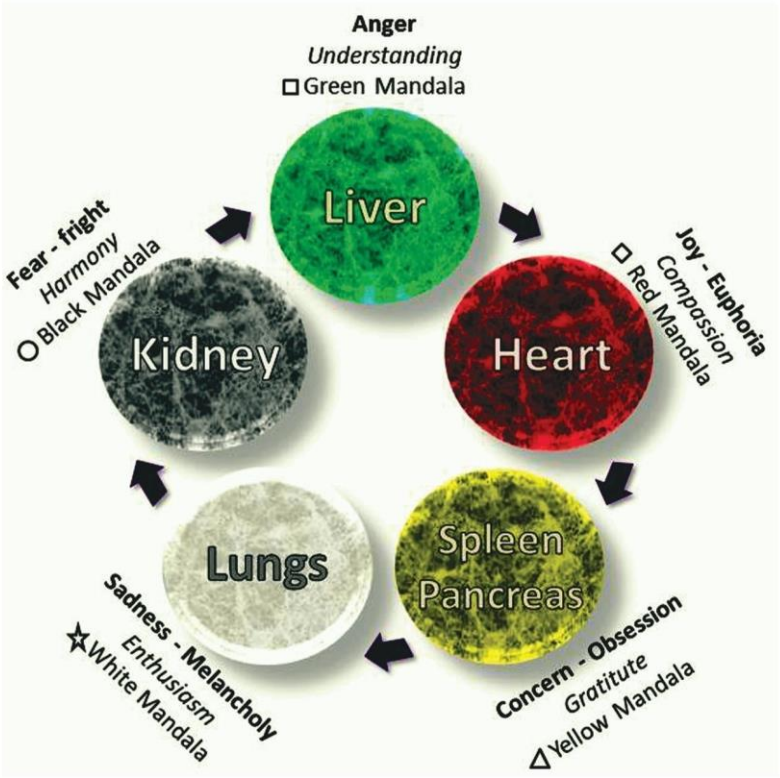

FIGURE 3.1 – Concepts of five colours, organs and emotions.

- *joy & euphoria/compassion,*
- *concern & obsession/gratitude,*
- *sadness & melancholy/enthusiasm,*
- *fear & fright/harmony.*
- *Welcome the first emotion that comes in your mind, do not try to justify or rationalize.*
- *Do not deny it, nor reject, just feel and welcome. See emotions as a way of learning.*[10]

10 Brief instructions to apply Mandalas of Emotions. © 2016 Mandalas of Emotions. Used with permission.

FIGURE 3.2 – Different composition of stones for each emotion.

4 Single Case Study

The patient was a 44-year-old Brazilian woman diagnosed with neuroendocrine tumour in the left breast in 2004. Neuroendocrine tumours (NETs) are neoplasms that arise from cells of the endocrine (hormonal) and nervous systems.[11] Several issues help define appropriate treatment of a neuroendocrine tumour, including its location, invasiveness, hormone secretion, and metastasis.

11 Keith Langley, "The Neuroendocrine Concept Today," *Annals of the New York Academy of Sciences* 733 (1994): 1–17.

FIGURE 3.3 – Applying mandalas of emotions (green mandala).

Treatments may be aimed at curing the disease or at relieving symptoms (palliative care). Clinical follow-up may be feasible for non-functioning low grade neuroendocrine tumours, whereas for intermediate and high-grade tumours (non carcinoids) are usually best treated by various early interventions (active therapy) rather than clinical follow-up. Treatments and outcomes have improved over the last decades. In malignant carcinoid tumours, the median survival rate has improved from two years to more than eight years.[12]

With regard to the patient in this report, she was prescribed an immediate mastectomy followed by radiotherapy in 2004, which proved to be effective at that time. However, in April 2013, a cancer recurrence was detected as a metastasis in the right adrenal and kidney, and small foci in lung and mediastinum. The patient was treated with injections of sandostatin during 18 months, a period in which clinical conditions remained stable. Also, the patient received two cycles of treatment with lutetium. After the second cycle, the patient had

12 Kjell Öberg and Daniel Castellano, "Current Knowledge on Diagnosis and Staging of Neuroendocrine Tumors," *Cancer and Metastasis Reviews* 30 (2011): 3–7.

a relapse. Two cancer foci were detected, one with a slow growth and another more aggressive in the mediastinum.

During the first semester of 2014, the patient started a treatment with Dr. Li Hui Ling, using Traditional Chinese Medicine. For a year, Dr. Ling provided this treatment once a week or once every two weeks by applying acupuncture. This treatment assisted the patient to re-establish a physical, mental and emotional balance as well as an increase in disposition. In October 2014, the patient started chemotherapy with cisplatin and etoposide, which proved efficient against the most aggressive tumour. During the first half of 2015, Dr. Ling began to apply the mandalas of emotions. This technique allowed the patient to build self-awareness in regard to her emotions, body and mind. Accordingly, there were rapid improvements in physical and emotional crises. In this sense, physical breakdowns related to emotional issues decreased as the patient's emotional resilience increased.

Ten months later, in August 2015, the patient had a relapse, with a stenosis at the entrance of the right lung. The suggested treatment with cisplatin chemotherapy and etoposide was ineffective. In December 2015, the physician prescribed preventive chemotherapy with xeloda and intermodal. Platelet and leukocyte levels decreased significantly and clinical conditions were stabilised.

Yet, in the last week of December (2015), *petechiae* (pinpoint flat round red spots under the skin surface caused by intradermal haemorrhage) were detected in the legs and feet, and platelets fell to 6,000 units per microliter of circulating blood (normally, you have anywhere from 150,000 to 450,000). The patient then stayed at the hospital on three occasions to receive four platelet transfusions. After the last hospitalization, the patient suffered panic attacks. The first episode began with extreme fear, shortness of breath and rapid heartbeat and lasted about 10 min. The patient was afraid of dark and enclosed places, but her physician felt that medication for panic attack was not an option due to the patient's clinical conditions. At that time, she self-discharged from the hospital because of panic attacks.

At home, Dr. Ling applied ME to countermeasure the feeling of fear. With a set of techniques, such as acupuncture, floral therapy and especially the stones placed as mandalas (with a frequent use of black and white mandalas), it was possible to re-establish a state of balance, during a process of self-awareness, sustaining the understanding of the healing process, which provided a clinical improvement and the reestablishment of platelet production by the bone marrow. The full confidence in Dr. Ling and her method is closely related to the patient's resilience, her constant emotional growth, and self-knowledge.

The patient was also instructed to use the mandalas of emotions at home, in order to sustain her welfare, avoiding thus the need to stay at the hospital.

Physical breakdowns related to emotional issues decreased as the patient's emotional resilience increased.

One week after the panic attack, platelets returned and rose slowly but steadily. In regard to the treatment with mandalas, the patient had presented unresolved matters related to emotional issues, which appeared as panic attacks. For this reason, the last and intensive intervention with mandalas after the panic attack focused on the understanding of emotions to improve coping mechanisms, as the patient states in the following transcript:

> I am glad to be at home and without medication. I am sure that my recovery will be more effective and fast. Mandalas are used daily with the help of Dr. Ling, considering my perception of emotions or physical frailty. They became an automatic tool embodied in my routine, and they help me to achieve balance and health.

5 Discussion

During cancer treatment, quality of life and self-esteem may decline considerably due to its great psychological burden. In this sense, strategies like add-on therapies are essential to avoid psychological breakdown that may compromise clinical improvement. Many side effects remain not only during active cancer treatment, but also for a short period thereafter, which can impact on psychological issues. The majority of disease-free cancer survivors report good quality of life one year post treatment, but still a significant number of survivors describe a lower overall physical well-being than those who had never experienced cancer.[13]

Medical institutions have continuously worked on establishing standards for quality, patient-centred cancer care that include recommendations for palliative care, distress management, and survivorship care planning.[14] These guidelines focus on comprehensive survivorship care, including support for health behaviour changes, and the assessment and management of the long-term and late effects of cancer and its treatment. Despite improvements in cancer treatment and survivor rates, many challenges remain. Miller and colleagues (2016) state that "future research should also focus on identifying the best methods

13 Kimberly D. Miller, Rebecca L. Siegel and Ahmedin Jemal, "Cancer Statistics 2016," *CA: A Cancer Journal for Clinicians* 66 (2016): 271–289.

14 Sloan and Gelband, *Cancer Control Opportunities in Low- and Middle-Income Countries,* 25.

for encouraging cancer survivors to adopt and maintain a healthy lifestyle".[15] In terms of emotions, many survivors suffer from a fear of recurrence.

In our case study, the patient faced a recurrence nearly ten years after her primary cancer. At this point, unresolved emotional issues came to the surface as panic attacks, compromising the treatment adherence and effectiveness. From our perspective, the major role of mandalas of emotions in this case was to promote greater self-awareness, through an understanding of emotional conflicts. The patient was able to cognitively approach these barriers during self-reflection mediated by stones placed as mandalas symbolizing each emotion she was experiencing. For example, a specific display of stones is chosen to represent fear and, during a period of meditation, the patient reflects upon what is causing this fear, how it started, what makes it stronger or decreases it, in order to consciously work on strategies to overcome this feeling.

A previous case control blind assessment study conducted by our research group on patients with epilepsy suggested that "Mandalas of Emotion" may facilitate perception of feelings, since there was a significant difference between groups (Control, n = 20; Intervention, n = 26). There was a significant change in perception of emotion in the group that received Mandalas of Emotions. Moreover, the group that received intervention had significantly more perception of body changes and became more relaxed when compared to the control group.[16]

When compared to other techniques, like meditation, mindfulness, and acupuncture; mandalas of emotions present the advantage of being a low cost and non-invasive method that could be quickly and easily self-applied in any situation or place. In terms of cognitive demand for learning and training, application is easier than other methods like mindfulness and meditation. Mandalas are adaptable to different contexts, since there are different displays of stones in order to work on different emotions.

Thus, this technique presents immediate results in a sense that it allows individuals to act upon their emotions, and a long-term improvement in the ability to sustain self-care, since it empowers the person with straight-forward strategies to understand and cope with emotions. In this sense, we believe that the mandalas of emotions can represent a significant contribution to promoting self-care and copying during and after cancer treatment.

15 Ibid.

16 Ribeiro, Carolina, et al. "Mandala of Emotions facilitate perception of feelings" (paper presented at the annual meeting of the Brazilian Research Institute for Neuroscience and Neurotechnology, Campinas, Brazil, April 11–13th, 2016).

6 Final Reflections

This single case illustrates the use of ME as add-on therapy for self-healing and resolution of internal conflicts for a long period of time. Although the reported findings cannot be generalized, these results bring a perspective of a therapeutic potential for situations of emotional conflict, to promote self-understanding and healing, enabling the person to better cope with these emotions. Therefore, this case report provides useful preliminary evidence to an accumulating body of literature supporting the theory and efficacies of add-on techniques in cancer treatment.

7 The Last Take

The experience described above presented during the Global Conference "The Patient", at Mansfield College, University of Oxford, the UK, in September, 2016, was shared with the patient. She was in the final stage of cancer, and in one of the last visits with Dr. Ling, in October 2016, before passing away in the following week, the patient was lucid and described her views on the overall experience with Mandalas of Emotions and living with cancer treatment, as follows (our translation):

> [During the final stage] my oncologist allowed me to stay home and to clinically follow-up my blood exams and platelets levels once every two weeks. My body no longer allows me to perform daily activities such as going to the supermarket or driving. But the main issue is emotional. I am constantly afraid that the pain may return, and, at those times when I need to go to the hospital, I fear the pain that the treatment may inflict on me. Mandalas of emotions is helping me to cope with this fear. I use the mandalas when I wake up and before going to bed. It is the kind of therapy, of self-healing tool, I need at this moment.

8 Acknowledgements

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Anexo II. A Proposal of Emotion Evocative Sound Compositions for Therapeutic Purposes, apresentado no 14th International Symposium on Computer Music Multidisciplinary Research (CMMR) Sound, Music and Motion, Marseille

A Proposal of Emotion Evocative Sound Compositions for Therapeutic Purposes

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Abstract. Recognition and understanding of emotions is a path for self healing. We have worked with Mandalas of Emotions, derived from the Traditional Chinese Medicine (TCM), as a complementary therapy. In this paper, we present the conceptual framework related to the creation of sound collages for the five elements of TCM and assessment of these compositions by experienced holistic therapists. Results present quantitative data, according to scales for relaxation, arousal and valence, and qualitative data from transcription and analysis of the recorded responses of volunteers. In our study, the most common perceptions were warmth, irritation, peace and fear. The innovation of this proposal may stimulate further research on emotion-evoking sounds, and in sound composition.

Keywords: Sounds, Music, Emotions, Integrative Therapies.

1 Introduction

Music and emotion has been long discussed, but systematic efforts to understand this relation are recent [1]. Its origin in the late 19th century occurs under a perspective of general psychology focused on psychophysics and experimental control. At this time, music psychology favored a more 'basic' perceptual and cognitive process related to music listening [2]. In the 1980s, Sloboda played an important role in developing the field of 'music cognition'. When his book, The Musical Mind [3], received recognition in the field, Sloboda had already started research in another field: music and emotion. Through a revival of Leonard B. Meyer's classic theory about musical expectations [4], Sloboda posed a correlation between 'cognition' and 'emotion'. Sloboda is now considered one of the driving forces in bringing 'music and emotion' to the spotlight, as a primary topic in music psychology [5].

Emotions, according to Koelstra et al. [6], are a psychophysiological process triggered by conscious and/or unconscious perception of an object or situation and are often associated with mood, personality, and motivation. Evoking emotions, including by means of music appreciation, is important to allow the recognition of feeling and to improve coping. In a healthcare service environment, sounds may be used as a masking tool, as a mean to improve patient-healthcare professional relation, and to

elucidate the emotional response to the current body and mind condition. This process may also mediate the creation of a therapeutic bound between patient and healthcare professional, the isolation of external sound interferences and improve patient experience and outcomes.

A specific dimensional approach for emotions, called the circumplex model of affection, proposes that all affective states result from two fundamental neurophysiological systems, one related to valence (a continuum of pleasure-dislike) and another to arousal or alertness [7]. According to the circumplex model, each emotion can be understood as a linear combination of two dimensions, or as varying degrees of valence and excitation. Joy, for example, is defined as an emotional state product of strong activation in the neural systems associated with valence or positive pleasure, together with the moderate activation in neural systems associated with excitation [8]. The affective states beyond joy also arise from the same two neurophysiological systems, but differ in the degree or extent of activation.

Specific emotions, therefore, arise from activation patterns within these two neurophysiological systems, along with cognitive interpretations and labeling of these central physiological experiences. Studies have applied the circumplex model to create and use musical parameters. In the study of Wassermann et al. [9], Sonification for Synthetic Emotions was used through the creation of an intelligent space, named as ADA. This artificial organism integrated a great number of sensorial modalities, so as to interact with the visitors through receptor systems. ADA used a language of sound and light to communicate their states of mind, emotions and behaviors.

We propose the use of circumplex model in a different context, in which we consider the five emotions based on Traditional Chinese Medicine (TCM), whose aims is to establishment a psychophysical balance. For this reason, the technique called Mandalas of Emotions (ME) applies nine steps to welcome emotions and develop abilities for reflection, as follows: identifying, accepting, accessing, revisiting, understanding, resignifying, reflecting, releasing emotions [10].

Fig.1. The cycle of mandalas in the sequence: spring/green, summer/red, high summer/yellow, autumn/white, winter/black.

For this process, this technique uses five colored, walnut-sized stones that are placed around the patient or on the person's abdomen for periods of 10 to 15 minutes, creating mandalas that correspond to five colors (green, red, yellow, white, black) and five emotions with its positive and negative correspondents (anger/comprehension, euphoria/ compassion, concern/gratitude, joy/ sadness, fear/courage) (Ling, 2013). These five colors establish a relation to the five seasons (spring, summer, high summer, fall, winter) and to the five functional systems (liver, heart, spleen and pancreas, lungs and kidney) [10], as depicted in Figure 1.

In this paper, we present the conceptual framework related to the creation of sound collages for the five Chinese elements (Wu Xing) and assessment of these compositions by holistic therapists. This relation was established by a strategy of sound collage, composing five pieces, one corresponding to each emotion.

Related work

Research has shown that sounds may translate emotions, as above mentioned, and also evoke emotions. In this sense, variations in sounds may elucidate what Huron [11] describes as the expectation-related emotion response system, which arouse corresponding limbic activations and contrasts.

Huron [11] defines five expectation-related emotion response systems: imagination (to motivate an organism to behave in ways that increase the likelihood of future beneficial outcomes), tension response (to prepare an organism for an impending event by tailoring arousal and attention to match the level of uncertainty and importance of an impending outcome), prediction response (to provide positive and negative inducements that encourage the formation of accurate expectations), reaction response (to address a possible worst-case situation by generating an immediate protective response), appraisal response (to provide positive and negative reinforcements related to the biological value of different final states). These concepts are applied in music composition in order to create absorbing sounds.

Moreover, psychologists describe the concept of entrainment as essential to perceive, react and enjoy music. Music, when considered as an external oscillator entraining a person's internal oscillators, potentially affects the sense of time and the sense of being in the world. Also, listeners exercise a great amount of their self-control in directing music entrainment, through unconscious processes and individual agency. Jones and colleagues published works between 1976 and 2002 on entrainment [12, 13]. This research considers three main assumptions on entrainment. First, human beings are considered inherently rhythmical, whose perception is capable of "tuning" with time patterns in the physical world. There is a tendency of synchronizing an individual's endogenous rhythms with perceived and expected rhythmic processes. Second, entrainment takes place as both period and phase present synchronization. At last, entrainment may vary in degrees.

In this paper, we illustrate the use of the Affective Slider[1] and other qualitative and quantitative data collection strategies performed to present sound compositions for expert assessment. Therefore, our methods section is intended to

[1] The Affective Slider, developed by Betella & Verschure [14] represents a model for data collection on reported valence and arousal, as described in the Methods Section. It is an advantage to use this model, since it will reflect a certain approximation to reality for experimental purposes.

support further studies with similar approaches. Results present quantitative data, according to scales for relaxation, arousal and valence, and qualitative data, which derive from transcription and analysis of the recorded responses of volunteers. In our study, the most common perceptions were warmth, irritation, peace and fear; drawing a parallel to its corresponding mandalas.

2 Methods

This section will present the method for creation of sound collages and its assessment by holistic therapists.

Creation of sound collages

We created five compositions, one for each mandala, using Audacity 2 with sound collages. These sound collages were chosen based in the elements of its corresponding mandala, which will be further elucidated in table 1. We also considered the stages of the relaxation process defined in the method, as three main phases (receive the emotion, reflect, and release the emotion). The duration of each composition was defined as 2.30 minutes, which creates a cycle that can be repeated for therapeutic purposes. Components followed the rationale described in Table 1.

Table 1. Elements, emotions, concepts and sound elements for each mandala.

Mandala	Elements	Emotions	Concepts	Sound elements
Green	Wood	Peace or Harmony	Beginning, birth of intentions	Shakuhachi and sound landscape of wind through bamboo
Red	Fire	Anxiety and confort	Growth, expansion	Sounds of hang drum, rattle and burning wood
Yellow	Earth	Gratitude and Concern	Harvest results	Sounds of two slowed hang drum rhythms
White	Metal	Joy and sadness	Reflection	Sounds of koshi bells and wind
Black	Water	Fear and courage	Conclusion	Sounds of ocean waves and rain

Original sounds have been altered from YouTube relaxation pieces to serve as samples and test the composition method. In order to create a database of sounds, we searched for videos on YouTube that presented a reference to the element of each mandala. For instance, wood is the element of the green mandala. The Japanese flute called Shakuhachi was chosen due to its relation to traditional knowledge and the possibility of having a melody with few notes, allowing collage-based techniques. We also used a sound of wind through bamboo to depict a sound landscape that posed a direct reference to wood and green, which the concept of mandalas (Table 1) associates with a calm and comprehensive atmosphere. For the red mandala, whose element is fire, there is a greater activity, with a rhythmic and repetitive melody, presented with a sound landscape of burning wood. This composition was expected to convey a feeling of warmth and a minor level of excitement or anxiety. For the yellow

mandala, we searched for sounds of traditional tribal drums as a reference to earth or desert, and we reduced the pace of the rhythm. For the white mandala, we searched for sounds created with metal, such as bells and chimes. At last, the black mandala comprises sounds related to water: sound waves, rain and a rain rattle.

The sound collages were organized to follow the nine stages of emotion recognition, as previously mentioned in the introduction section (identifying, accepting, accepting, accessing, revisiting, understanding, resignifying, reflecting and releasing emotions), which were comprised in three main steps: identify, revisit and release. Translated into sound composition, we created the rationale depicted in Figure 2 below.

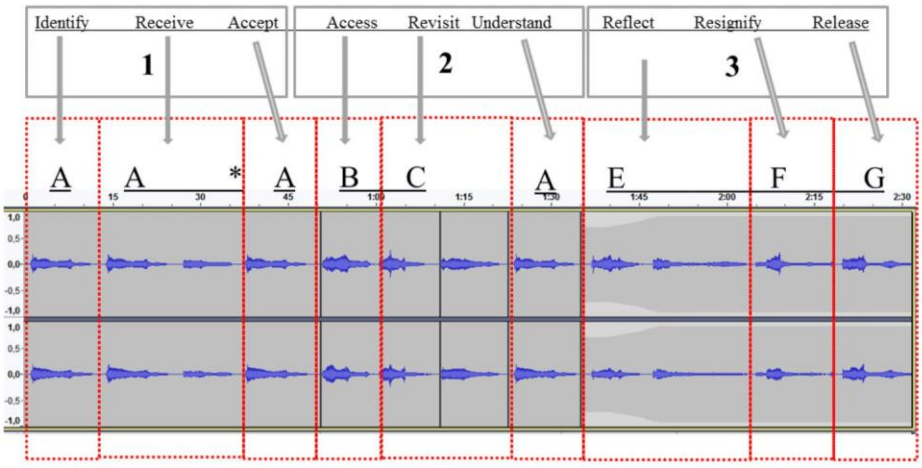

Fig. 2. The figure illustrates a print from the Audacity 2, in which A represents the arrival of the emotion, repeated throughout the composition.

In the next stage of this study, these collages will be reformulated, using original sounds and instruments, in order to be released for therapeutic purposes.

Assessment by holistic therapists

This study was performed with 8 participants on June 2018 from 8 am to 6 pm, with sessions of 30 minutes with each volunteer. In terms of sample size, we applied the first round of the Delphi method for validation of materials with experts as described by Alexandre and Colucci [15]. Selection process of volunteers included only professionals with more than one year of experience in applying Mandalas of Emotions, after signing an Informed Consent Term under Ethics Committee approval from University of Campinas. We prepared a controlled environment in which the volunteer laid down and listened to the compositions with a Microsoft Headset LX-3000. The volunteer listened to the 2.30 minutes samples in a randomized order, which was unknown to the researcher who performed the experiment.

Data collection started with questions regarding relaxation (visual Likert-scale, which ranges from 1, not relaxed, to 5, completely relaxed), valence and arousal levels with a validated visual scale called Affective Slider, that we printed in A4 white sheets to be marked with a pencil [14]. According to these authors, the "Affective Slider" (AS) is "a digital self-reporting tool composed of two sliders that measure arousal (top) and pleasure (bottom) on a continuous scale. The AS does not

require written instructions and it is intentionally displayed using a neutral chromatic palette to avoid bias in ratings due to the emotional connotation of colors".

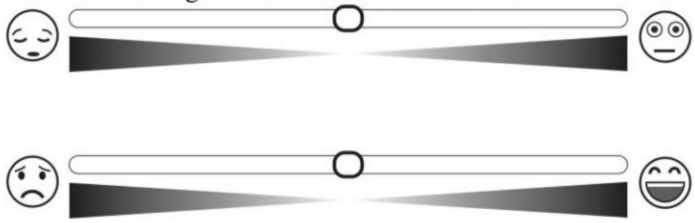

Fig. 3. This original Affective Slider is used in a touch-screen device, that allows to scroll the marker, placed in the center of each scale. We deleted this marker, printed this scale and instructed the participant to mark with a pencil.

Each mark on these scales was converted in centimeters, in order to elaborate graphs for further analysis. See the experiment flow in Fig. 4.

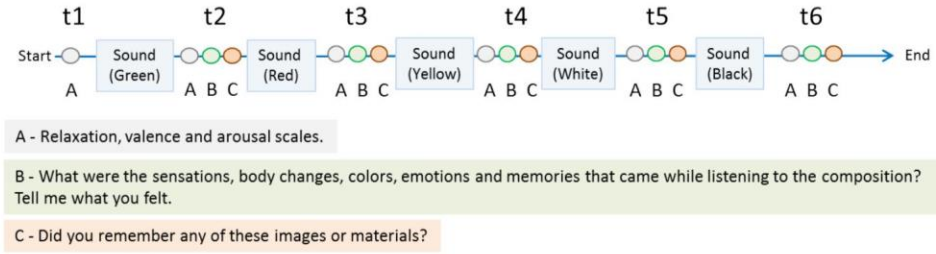

Fig. 4. Illustration of the experiment flow. The first period of data collection (t1) to the last (t6); A, B and C represent the qualitative and quantitative data collection questions and each box shows the presentation of sound. For each volunteer, the order of these compositions was different, in a randomized distribution. The sound was also unknown to the researcher who collected data.

Before listening to any composition, participants fulfilled the scales as mentioned in step A. In B, the researcher asked the volunteer response considering its body and mind perceptions, which include memories and colors. In C, the researcher presents a series of images (Fig.3) and materials (Fig.4) that represent each element (wood, fire, earth, metal and water) in forms that correspond to those used in the compositions. Those images and elements are depicted in figures 3 and 4. This strategy aimed to recall timbre perceptions, using these materials to enable characterizing the musical perception, once that volunteers did not present a background in musical knowledge.

Fig. 5. Pictures presented to volunteers that corresponded to elements of timbre in each composition.

Fig. 6. Materials presented to volunteers corresponded to elements of timbre in each composition.

Results

This section will present quantitative results, according to data collected using the scales for relaxation, arousal and valence, and qualitative data, which derives from transcription and analysis of the recorded responses of volunteers.

Quantitative results

Volunteers presented the level of relaxation in a continuous scale that ranged from 0 to 100 millimeters, marked with five possibilities of levels (1 = not at all, 5 = very much). Data in figure 5 represents measurement from the first period (t1) to the last (t6). Results show a progressive relaxation effect throughout the experiment, with a plateau between t5 and t6. It is important to mention that the compositions were in a randomized order; therefore, graph 1 depicts the isolated effect of the experiment, showing that any combination of compositions provokes a similar outcome throughout time.

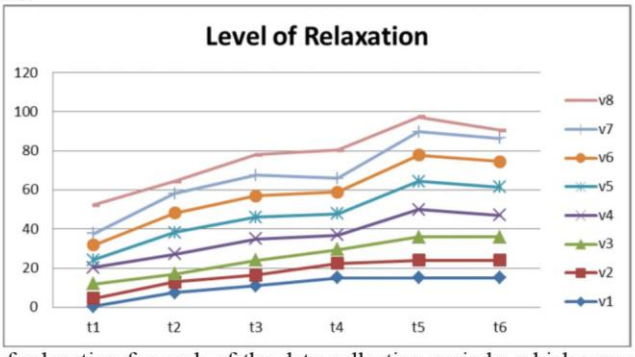

Fig. 5. Level of relaxation for each of the data collection periods, which range from t1 to t6. The initial period (t1) depicts the volunteer's baseline, before any sound intervention.

Volunteers were also required to fulfill the Affective Slider scale, which was printed in a paper, indicating with a pencil the current position of their arousal level, as shown in Fig. 6. The same was performed for valence (Fig.7). In these graphs, we present the isolated results per composition (green, red, yellow, white or black).

Considering media and standard deviation, results indicate a greater effect in terms of arousal variations in the following order: white, 0.7 (1.3); black, 0.3 (1.5); green, 0.4 (2.0); red 0.3 (1.5); yellow, 0.0 (2.0) and in terms of valence variations:

green, 2.35 (2.2); white 1.1 (2.0); red, 0.55 (0.75); black, 0.1 (2.1) and yellow, 0.0 (1.5). For therapeutical purposes, arousal levels must present a minor change, since the subject is expected to have a steady state of mind and body but, at the same time, present a variation related to the emotion-evoking process.

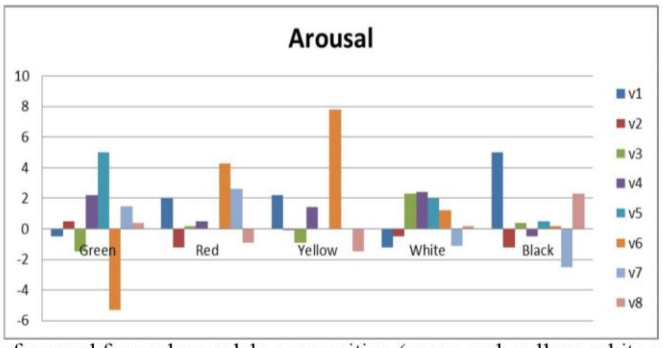

Fig. 6. Level of arousal for each mandala composition (green, red, yellow, white and black) and volunteers (v1 to v8).

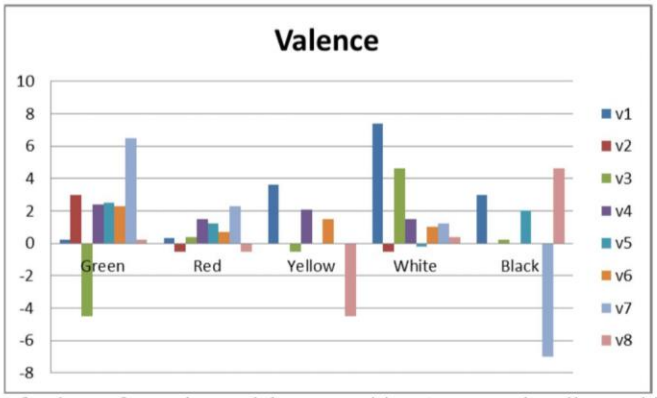

Fig. 7. Level of valence for each mandala composition (green, red, yellow, white and black) and volunteers (v1 to v8).

Qualitative results

For each period illustrated in the figure 1, that depicts the experiment flow, we asked questions that would convey the perceptions of our volunteers. For each composition, volunteers were asked to describe it as an emotion. We present this data in the form of a word cloud in figure 8, showing a wide range of outcomes.

Fig. 7. Results of the question "Which emotion arouse when listening to the sound composition?". Created with <https://www.wordclouds.com/>

Responses to questions B and C: "What were the sensations, body changes, colors, emotions and memories that came while listening to the compositions?" and "Did you remember any of these images or materials?", respectively, were analyzed for each composition in order to convey the main topics of outcomes, as described in the following paragraphs and in table 2.

In general, the composition of the green mandala brought a feeling of opening, beginning, with light tones. Six of eight volunteers pointed out as very relaxing, and that it should be the first of all compositions. According to volunteers, this sound referred to the green, wood, bamboo, as well as the desert and the vastness. These perceptions confirm that specialists related this composition to the green mandala. The sound of the red mandala was indicated by 7 of the 8 volunteers as related to warmth, comfort. Volunteers attributed this sensation to the cracking of fire sounds, but referred that its intensity could be reduced.

Specialists related the composition of yellow mandala to elements of earth (sand), wind, wood, and feelings of trust and gratitude. The sound of the white mandala brought elements of metal, water, wind, peace, but also irritation and anxiety associated with metallic sounds. Volunteers suggested reducing the information in this mandala. The sound of the black mandala was related to the sounds of waves, sand and also fear. Participants referred that there were several elements in this composition, and that these could be reduced.

Table 2. Responses for emotions, colors, elements and memories indicated by volunteers for each sound composition.

Mandala	Volunteers report
Green	Emotion: hope, peace, calm. Colors: light colors, green. Elements: bamboo, wood. Memories: forest, wind.
Red	Emotions: trust, gratitude, good memories. Colors: red, dark colors. Elements: fire. Memories: fire, bonfire.
Yellow	Emotions: peace, irritation, anxiety.

	Colors: light and warm colors. Elements: sand. Memories: wide field, horses.
White	Emotions: peace, irritation, anxiety. Colors: dark, blue, black. Elements: metal, water. Memories: wind, desert.
Black	Emotions: fear, irritation, affliction, determination. Colors: black, yellow, blue, dark. Elements: sand, water. Memories: storm, beach.

Discussion

This study presents the application of a method to assess specialists' response to collage-based compositions. These compositions are related to the five emotions derived from the Traditional Chinese Medicine (see table 1). Quantitative and qualitative data conveyed participants' perceptions and suggestions concerning the sounds, which will be later considered to compose the final version of each mandala.

The composition aesthetics followed characteristics of American Minimal Music and music commonly used for therapeutic purposes. According to a systematic review of randomized controlled trials that applied music interventions in a Neonatal Intensive Care Unit (NICU), music for therapies should be "soothing and not use too many different elements in terms of instruments, rhythms, timbres, melodies and harmonies" [16]. Considering this definition, the review study shows that the preferable choice of music is a lullaby, softly sung or played on an instrument. Also, we understand that familiarity plays an important role in music appreciation, so this strategy aimed at creating some degree of recognition related to a music style. In a study by Pereira et al. [17], brain activation data revealed that broad emotion-related limbic and paralimbic regions as well as the reward circuitry were significantly more active for familiar relative to unfamiliar music.

Instead of presenting a classification of emotions for participants to choose from, we performed open-ended questions, which were recorded and later analyzed. We also used physical elements and images related to elements of the five emotions to question whether participants identified sound landscapes and concepts applied in compositions. When comparing results in table 2 with emotions in table 1, we may state that there is a considerable parallel, and adjustments that can be implemented to reduce unwanted reactions, such as irritation.

Considering that these compositions allowed emotion arousal, as described in the Results section, we may compare our findings to those of Sloboda [18]: seventy-six college students were asked to indicate which of 25 emotions they had experienced to music. Sadness and joy were the two emotional states experienced by most listeners (96.2 and 93.4 percent, respectively). In our study, the most common perceptions were warmth, irritation, peace and fear as shown in Figure 2. We understand that the emotion of joy (55%) may be related to feelings of gratitude, welcoming, peace, comfort and calm, whereas sadness (37%) may be associated with fear, affliction, not to mention the report of "sadness" itself (See figure 7).

Limitations of this study are related to the sample size, which could be later expanded, and the application of only one round with experts. Once we apply changes

in the compositions, we expect to organize a second round of experts' assessment to validate our compositions. Our results are limited to the self-reported perceptions of volunteers, using visual scales that may not correspond to physiological changes in arousal and valence. Since this research project is under development, at some point, new research could be incorporated in this study. Also, quantitative and qualitative methods of conveying perception may be later complemented by physiological measures, such as heart rate and skin conductance, and, if applicable, brain activation experiments.

Conclusion

Mandalas of Emotions derive from a secular culture, Chinese Medicine, and establish a bridge between East and West for a need as ancient and complex as human beings: self-healing. Evoking, communicating and understanding emotions have been widely developed through integrative therapy and music, paths to reestablish a balance in the body and mind. The creation of sound compositions based in an emotion-evoking therapy may enhance its potential and, therefore, the possibility of self-healing.

This study provides a conceptual framework for creation of sound collages and testing of these with experts, based in Mandalas of Emotions. The innovation of this proposal may stimulate further research on emotion-evoking sounds, in sound composition and, possibly, in computational music. We understand that the creation of modulated music and systematization of sounds must be preceded by a process of applying and validating a conceptual framework, which could be pursued as we proposed. In the next stages of this ongoing project, we intend to use a music software tool to transform these compositions based on the listener's response in real time, and improve data collection methods.

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Anexo III

Mandalas das emoções para enfrentamento do sofrimento psíquico de pacientes com doenças crônicas e vulneráveis no sistema único de saúde: estudo de caso

Mandalas of emotions to face the psychic suffering of patients with chronic and vulnerable diseases in the public health system: case study

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Apresentado na III Jornada de Práticas Integrativas e Complementares em Saúde: Evidências Científicas, promovida pelo Grupo Estudo das Práticas Integrativas Complementares em Saúde, na Escola de Enfermagem da Universidade de São Paulo, no dia 05 de outubro de 2018, na modalidade Oral.

Introdução: As Mandalas das Emoções® tem como referência preceitos teóricos da Medicina Tradicional Chinesa, como as cinco cores (verde, vermelho, amarelo, branco e preto) e cinco emoções com seus correspondentes negativos e positivos (ansiedade/compreensão, agitação/compaixão, preocupação/gratidão, tristeza/alegria, medo/coragem) (Ling, 2013). Por meio da abordagem de cada uma dessas emoções representadas pelas cores de mandalas, o intuito desse estudo é viabilizar a reflexão e trabalhar as emoções de pessoas com epilepsia e seus familiares, parte de um projeto de doutorado. Métodos: O recrutamento ocorreu no Ambulatório de Neurologia de um hospital de ensino, com aprovação do Comitê de ética (64276116.4.0000.5404), mediante o pedido do contato telefônico de pessoas com epilepsia e familiares. Os seis encontros quinzenais das 10h30 às 12h entre agosto e outubro de 2017 possibilitaram trabalhar cada uma das cinco mandalas e suas respectivas emoções associadas, mediados por duas enfermeiras e por uma estudante de psicologia, com o apoio à distância da médica criadora da técnica. Os participantes receberam um caderno com explicação sobre o método e para o registro diário de sua aplicação, cartões coloridos para formar as mandalas. A cada encontro, explanou-se sobre uma das cinco emoções e suas polaridades. Os participantes foram orientados a fechar os olhos e, durante 8 minutos, refletir sobre as questões: “(i) Já sentiu isso (a emoção)? (ii) Com que frequência? (iii) Você se lembra de alguma situação? (iv) Como você reagiu? (v) Você acha que poderia ter reagido diferente? De que forma?”. Após esse período, os participantes compartilharam sobre sua reflexão e novas perspectivas. Resultados: Das 30 pessoas convidadas, doze confirmaram presença, quatro compareceram e duas concluíram as seis sessões, uma pessoa com epilepsia e sua mãe. As Mandalas despertaram emoções relacionadas a períodos de grande instabilidade clínica, familiar e pessoal: o pós-operatório da retirada de um tumor no cérebro, o qual desencadeou a epilepsia; ao período de um mês em que a paciente, então gestante, ficou em coma após queda por conta de

crise epiléptica, ocasionando a perda do bebê; como também relacionada à separação do marido e ao retorno à casa de sua mãe. A mãe, por sua vez, relatou diversas emoções devido ao estado clínico da filha. As participantes demonstraram desenvolvimento progressivo de estratégias para lidar com as emoções. Conclusões: As sessões e o registro no caderno, mediados pelas Mandalas, possibilitaram a conscientização sobre as emoções vivenciadas pelo paciente com epilepsia e seu familiar. Tal exercício conferiu um distanciamento entre a emoção e o indivíduo e melhor domínio sobre as emoções nas tomadas de decisão e relações interpessoais. A epilepsia é uma doença neurológica crônica, um problema de saúde pública, a qual ocasiona uma grande carga psicossocial aos pacientes, associada à imprevisibilidade das crises e ao estigma. Nesse contexto, as Mandalas das Emoções® constituem uma ferramenta de baixo custo, fácil aprendizagem, a qual pode ser aplicada em larga escala no Sistema Único de Saúde, com o intuito de promover a melhora da saúde mental e alívio do sofrimento psíquico em doenças crônicas e vulneráveis. O presente trabalho foi realizado com apoio da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES), Código de Financiamento 001.

Palavras-chave: Epilepsia, Terapias Complementares, Medicina Tradicional Chinesa, Autocuidado.

Referências: Ling LH. Dialogando com as emoções e promovendo a saúde. Curitiba: Insight, 2013.

Anexo IV – Parecer do Comitê de Ética

UNICAMP - CAMPUS CAMPINAS

PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Dialogando com os sentimentos de pacientes com epilepsia pelas Mandalas das Emoções

Pesquisador: LI LI MIN

Área Temática:

Versão: 3

CAAE: 64276116.4.0000.5404

Instituição Proponente: Hospital de Clínicas - UNICAMP

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 2.137.976

Apresentação do Projeto:

Introdução:

A epilepsia é a condição neurológica crônica mais comum em todo o mundo, com uma prevalência de 9,2 a cada 1000 pessoas (Guerreiro, 2000). Impõe um peso grande nas áreas psicológica, física, social e econômica, revelando dificuldades não só individuais, mas também familiares, escolares e sociais, especialmente devido ao desconhecimento, crenças, medo e estigma. Quando comparados a pessoas sem epilepsia, os pacientes com epilepsia apresentam, em especial: maior isolamento social, maior dificuldade nos relacionamentos sociais e maiores índices de desemprego. Por isso, é importante que as pessoas conheçam a epilepsia, suas implicações práticas, as dificuldades psicológicas associadas para que as pessoas com epilepsia e suas famílias deixem de ser vítimas de preconceito e estigma (Fernandes et al., 2007). Neste contexto, torna-se essencial traçar estratégias de intervenção. A fim de garantir os direitos e a inclusão social de pessoas com epilepsia, associações e organizações não governamentais foram criadas, desempenhando um papel essencial no apoio às pessoas com epilepsia na luta contra o preconceito, um resultado da falta de conhecimento. Perante essa dificuldade, desenvolveu-se o Grupo de Interação Social (GIS) para profissionais de saúde e pessoas em geral interessadas no tema, tendo como base algumas terapias já existentes (Fernandes et al., 2007). O GIS teve como

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objetivo ampliar a abrangência no manejo integral das epilepsias, visando quatro dimensões: grupos de reflexão, atividade esportiva lúdica, terapia cognitivo comportamental e medicina tradicional chinesa. Para isso, o grupo foi realizado num período de quatro horas, cobrindo os seguintes temas: manejo da epilepsia (o que é epilepsia, o que são crises epilépticas, as causas e as formas de tratamento, impacto psicossocial, reinserção social) e estratégias para formação de grupos de epilepsia na comunidade. Apesar dos resultados não mostrarem diferenças estatisticamente significativas, possivelmente em decorrência do número pequeno de sujeitos, pode-se observar uma melhora em todos os itens avaliados: habilidades sociais, autoestima, resiliência e percepção de estigma na epilepsia, conforme descrito por Fernandes et al.(2007). Em decorrência da experiência, o GIS se consolidou como uma ferramenta muito versátil e de fácil empoderamento, trazendo benefícios para a população. Durante essa prática, de suma importância, notou-se a dificuldade dos pacientes de expressar suas emoções. Uma das autoras do trabalho, a Dra. Ling, desenvolveu o método chamado "Dialogando com as emoções", baseado na Medicina Tradicional Chinesa (MTC) voltada para despertar a consciência da emoção e facilitar que o paciente reconheça e trabalhe essas emoções, para que comece a lidar com os conflitos internos. Esta técnica utiliza cinco pedras coloridas, do tamanho de uma noz as quais são colocadas ao redor dos pacientes e em algumas vezes sobre o abdômen da pessoa (Ling, 2013). Através das Mandalas das Emoções (ME), os pacientes são guiados para uma conexão com o interior, despertando as possibilidades de autocura (resiliência). De acordo com Ling (Dialogando com as Emoções e Promovendo Saúde), a cura corresponde a uma nova consciência, uma nova atitude diante das situações. Durante o atendimento, a autora relata que as sensações percebidas podem incluir: formigamento, calor, pulsação no local dos cristais ou despertar de certas lembranças. Segundo a MTC, através das emoções o indivíduo expressa como se sente tanto em relação ao corpo quanto à mente. Na definição de bem-estar segundo a MTC, não basta a ausência de queixas físicas, é preciso uma harmonia nas esferas física, emocional e mental. As Mandalas das Emoções usam as teorias de 5 movimentos, 5 emoções, 5 cores, Ying/Yang e as 5 direções para compor esse método. A dinâmica de conversar sobre as emoções trouxe a necessidade de aprofundar a questão de conscientização individual sobre as emoções. A técnica das ME com base nas premissas da medicina tradicional chinesa pode facilitar o reconhecimento das emoções pelos seus usuários, entretanto, não é claro qual é a porcentagem em que isso acontece. Para isso, há uma necessidade de investigar os efeitos terapêuticos dessa técnica.

Hipótese:

As Mandalas das Emoções podem ajudar a facilitar o entendimento dos conflitos emocionais em

pacientes com epilepsia.

Metodologia Proposta:

Estudo 1 - Grupo "Dialogando com as emoções através das mandalas" Esse grupo será realizado com pacientes e acompanhantes às quintas-feiras das 12h-13h no Ambulatório de Neurologia do HC-UNICAMP com o apoio de enfermeiras e psicólogas para promover o apoio e a construção do conhecimento sobre a doença, de maneira a levantar quais são as emoções associadas à epilepsia através da análise do conteúdo das sessões. Para isso, as sessões serão gravadas perante o consentimento e assinatura do termo de consentimento livre e esclarecido, em conformidade com o Comitê de Ética da Faculdade de Ciências Médicas. Somente serão transcritos os áudios daqueles participantes que assim autorizarem. Os áudios serão transcritos e analisados quanto aos principais temas abordados no grupo. A gravação de áudios será realizada até o número amostral dos participantes atingir 210 voluntários, no período máximo de dois anos. Estudo 2 – Grupo de acompanhamento com as Mandalas das Emoções Esse grupo será realizado com pacientes e acompanhantes às quintas-feiras das 10h30-12h no ambulatório do Hospital de Clínicas da UNICAMP com o apoio de enfermeiras e uma graduanda em Psicologia para realizar a capacitação para utilizar Mandalas e acompanhar durante um total de seis encontros, um a cada 15 dias. Serão recrutados 15 voluntários para cada ciclo de seis encontros (3 meses), e serão realizados 6 ciclos ao longo de 2 anos, abrangendo um total de 90 voluntários. No primeiro encontro, será realizada uma avaliação através de um questionário estruturado, incluindo o diário de crise, a escala de Qualidade de Vida do paciente com epilepsia com 31 questões, a serem analisadas com testes não paramétricos (Mann-U-teste, Wilcoxon) e qui -quadrado, assim como o preenchimento do Termo de Consentimento Livre e Esclarecido. O questionário de Qualidade de Vida será aplicado novamente após as seis sessões. Em cada encontro, serão trabalhadas uma das cinco emoções, representadas por cinco cores em cartões. Através de uma votação, o grupo vai escolher a emoção a ser trabalhada de acordo com a cor do cartão. Cada pessoa vai retirar sua própria carta, da cor que está sendo trabalhada pelo grupo, deve escrever a emoção no post-it e grudar no cartão. Antes de abrir a roda para conversa cada participante deverá olhar para cor do cartão e para a emoção escolhida e refletir se: 1. Já sentiu isso? 2. Com que frequência? 3. Lembra de alguma situação? 4. Como você reagiu? 5. Você acha que poderia ter reagido diferente? De que forma? Depois de uma reflexão individual sobre as perguntas, abre-se a discussão para o grupo. No fechamento de cada encontro, o coordenador montará a mandala corresponde no centro da sala. Cada participante deverá focar na cor central da mandala e refletir sobre tudo o que foi falado. Esse processo será repetido seguindo a sequência das cores: verde, vermelho, amarelo, branco e

preto. Após a dinâmica, o participante será orientado sobre uma tarefa de casa. Após o encontro, em casa, o participante será convidado a refletir sobre a situação lembrada na questão 4, de maneira a pensar como poderia ter agido de outra forma e se houve outras situações e escrever em um diário sobre sua reflexão. Essa reflexão será discutida no início do próximo encontro. Os voluntários serão contatados via telefone e via aplicativo WhatsApp para eventuais dúvidas na execução das mandalas e para estimular a realização das tarefas de casa (padronizadas como: "Você tem alguma dúvida sobre a aplicação das mandalas?", "Lembre-se de realizar a tarefa de casa de nosso último encontro" e "Lembre-se de nosso encontro amanhã às 10h30 no Ambulatório de Neurologia do HC-UNICAMP"), o conteúdo das mensagens não será utilizado para fins de pesquisa. Ao término dos cinco encontros, será realizada uma breve avaliação através das perguntas no instrumento de coleta de dados anexo a este projeto. Critério de Inclusão: • Adultos com mais de 18 anos (não há limite máximo de idade); • Os pacientes que participaram do Ambulatório no dia do recrutamento; • Somente para o estudo 2, pacientes que consentirem com o acompanhamento durante a pesquisa através de mensagem por celular e fizerem uso de aplicativo do Whatsapp. Critério de Exclusão: O participante não pode entrar no estudo, se qualquer um dos seguintes se aplicarem:• Menores de 18 anos de idade;• não comparecer no Ambulatório como um paciente nos últimos 12 meses;• Pacientes com outras co-morbidades que podem influenciar a coleta de dados de acordo com recomendações clínicas.

Objetivo da Pesquisa:

Objetivo Primário: a) Avaliar as questões emocionais em pacientes com epilepsia; b) Avaliar se a técnica Mandalas das Emoções pode ajudar a facilitar o entendimento dos conflitos emocionais.

Objetivo Secundário: Resultados específicos Este projeto fornecerá três resultados:1. A nível de assistência à saúde: material didático para a disseminação da técnica Mandalas das Emoções. Este projeto visa estruturar uma técnica para reconhecer e lidar com as emoções, permitindo assim que pacientes tenham acesso e apliquem de forma independente e contínua. 2. Área acadêmica e de pesquisa: os resultados serão apresentados em conferências nacionais e internacionais, assim como eles serão publicados em periódicos acadêmicos.3. Educação: uma aluna de pós-graduação será envolvida na coleta de dados, estabelecendo uma oportunidade para desenvolver a investigação.

Avaliação dos Riscos e Benefícios:

Segundo informações do pesquisador:

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Benefícios: 1. Assistência à Saúde: os resultados da pesquisa relacionados com as emoções da pessoa com epilepsia pode levar a um melhor entendimento sobre essa condição, assim como a investigação sobre os efeitos benéficos das Mandalas das Emoções. 2. Área acadêmica e de pesquisa: os resultados serão apresentados em conferências nacionais e internacionais, assim como serão publicados em periódicos acadêmicos. Proporcionando cada vez mais um entendimento sobre o estigma na epilepsia e uma melhor possibilidade de auxilio a pessoas que se encontram nesta condição. 3. Educação: alguns alunos serão envolvidos na coleta de dados, estabelecendo uma oportunidade para desenvolver a investigação científica. Influenciando os alunos a pesquisar cada vez mais sobre a epilepsia.

Comentários e Considerações sobre a Pesquisa:

Este protocolo se refere ao Projeto de Pesquisa intitulado " Dialogando com os sentimentos de pacientes com epilepsia pelas Mandalas das Emoções", cujo Pesquisador responsável é o Prof. Dr. LI LI MIN com a colaboração das pesquisadoras participantes Gabriela Salim Spagnol e Carolinne Yuri Tagami. A pesquisa foi enquadrada na Área Ciências Biológicas e embasará a Tese de Doutorado da pesquisadora Gabriela Salim Spagnol. A Instituição Proponente é o Hospital de Clínicas - UNICAMP. Segundo as Informações Básicas do Projeto, a pesquisa tem orçamento estimado em R$500,00 (quinhentos reais) e o cronograma apresentado contempla início do estudo 01/09/2017, com término em 01/08/2019. Serão abordadas ao todo 300 pessoas, sendo 210 do Grupo focal “Dialogando com as emoções” e 90 do grupo Grupo de acompanhamento com as Mandalas das Emoções.

Considerações sobre os Termos de apresentação obrigatória:

Foram anexados os seguintes documentos:

1-Folha de rosto:folha_Mandalas_Epilepsia.pdf 10/11/2016 17:34:50
2-Projeto detalhado:Projeto20170619v2.pdf 21/06/2017 16:42:52
3-Informações básicas do projeto:PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_822874.pdf 21/06/2017 16:47:09
4-TCLE:TCLE_20170619_v2.pdf 21/06/2017 16:43:02
5-Comprovante de vínculo:lilimin.png 09/01/2017 09:12:01
6-Brochura do pesquisador:Anexo_Protocolodepesquisa_Mandalas_20170607.pdf 07/06/2017 15:59:43
7-Carta resposta:Carta_ao_CEP_20170619v2.pdf 21/06/2017 16:43:20

Conclusões ou Pendências e Lista de Inadequações:

Todas as pendências foram atendidas.

Considerações Finais a critério do CEP:

- O participante da pesquisa deve receber uma via do Termo de Consentimento Livre e Esclarecido, na íntegra, por ele assinado (quando aplicável).

- O participante da pesquisa tem a liberdade de recusar-se a participar ou de retirar seu consentimento em qualquer fase da pesquisa, sem penalização alguma e sem prejuízo ao seu cuidado (quando aplicável).

- O pesquisador deve desenvolver a pesquisa conforme delineada no protocolo aprovado. Se o pesquisador considerar a descontinuação do estudo, esta deve ser justificada e somente ser realizada após análise das razões da descontinuidade pelo CEP que o aprovou. O pesquisador deve aguardar o parecer do CEP quanto à descontinuação, exceto quando perceber risco ou dano não previsto ao participante ou quando constatar a superioridade de uma estratégia diagnóstica ou terapêutica oferecida a um dos grupos da pesquisa, isto é, somente em caso de necessidade de ação imediata com intuito de proteger os participantes.

- O CEP deve ser informado de todos os efeitos adversos ou fatos relevantes que alterem o curso normal do estudo. É papel do pesquisador assegurar medidas imediatas adequadas frente a evento adverso grave ocorrido (mesmo que tenha sido em outro centro) e enviar notificação ao CEP e à Agência Nacional de Vigilância Sanitária – ANVISA – junto com seu posicionamento.

- Eventuais modificações ou emendas ao protocolo devem ser apresentadas ao CEP de forma clara

e sucinta, identificando a parte do protocolo a ser modificada e suas justificativas e aguardando a aprovação do CEP para continuidade da pesquisa. Em caso de projetos do Grupo I ou II apresentados anteriormente à ANVISA, o pesquisador ou patrocinador deve enviá-las também à mesma, junto com o parecer aprovatório do CEP, para serem juntadas ao protocolo inicial.

- Relatórios parciais e final devem ser apresentados ao CEP, inicialmente seis meses após a data deste parecer de aprovação e ao término do estudo.

-Lembramos que segundo a Resolução 466/2012 , item XI.2 letra e, "cabe ao pesquisador apresentar dados solicitados pelo CEP ou pela CONEP a qualquer momento".

-O pesquisador deve manter os dados da pesquisa em arquivo, físico ou digital, sob sua guarda e responsabilidade, por um período de 5 anos após o término da pesquisa.

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_822874.pdf	21/06/2017 16:47:09		Aceito
Recurso Anexado pelo Pesquisador	Carta_ao_CEP_20170619v2.pdf	21/06/2017 16:43:20	LI LI MIN	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE_20170619_v2.pdf	21/06/2017 16:43:02	LI LI MIN	Aceito
Projeto Detalhado / Brochura Investigador	Projeto20170619v2.pdf	21/06/2017 16:42:52	LI LI MIN	Aceito
Brochura Pesquisa	Anexo_Protocolodepesquisa_Mandalas_20170607.pdf	07/06/2017 15:59:43	LI LI MIN	Aceito
Outros	lilimin.png	09/01/2017 09:12:01	LI LI MIN	Aceito
Folha de Rosto	folha_Mandalas_Epilepsia.pdf	10/11/2016 17:34:50	LI LI MIN	Aceito

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

CAMPINAS, 26 de Junho de 2017

Assinado por:
Renata Maria dos Santos Celeghini
(Coordenador)

Endereço: Rua Tessália Vieira de Camargo, 126
Bairro: Barão Geraldo **CEP:** 13.083-887
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Anexo V - Autorização para reproduzir os capítulos publicados pela Brill

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Ter, 07/01/2020 10:44

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Cc: Jytte Holmqvist <kastanjett@gmail.com>

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Best,

Jason

Jason Prevost
Acquisitions Editor
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Sent: Saturday, January 4, 2020 9:44 AM
To: Publicationethics <publicationethics@brill.com>
Cc: Jytte Holmqvist <kastanjett@gmail.com>
Subject: The Patient-Doctor Dynamics Chapters

Dear all,

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Please, I need your assistance in one matter regarding copyright.

I published two book chapters on "The Patient-Doctor Dynamics",
see: https://brill.com/view/title/39411, entitled:

Mandalas of Emotions as Add-on Therapy for Self-Healing and Resolution of Internal Conflicts in Cancer Treatment

“Dialogue with Emotions” through the Eyes of Patients with Epilepsy and Caregivers

These chapters are part of my doctoral thesis at University of Campinas and I need to include them in my thesis that will be available at the university's library (online and printed) with no commercial purpose.

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Gabriela Spagnol
RN MSc PhD candidate
School of Medical Sciences
University of Campinas, Brazil

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Instructor name	Li Li Min		

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Volume of serial or monograph	Epilepsy & Behavior 93 (2019)		
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Protocol Registration and Results System

ClinicalTrials.gov Protocol Registration and Results System (PRS) Receipt
Release Date: February 12, 2020

ClinicalTrials.gov ID: NCT04220333

Study Identification

Unique Protocol ID:	64276116400005404
Brief Title:	Randomized Control Trial on Mandalas of Emotions (ME)
Official Title:	Randomized Control Trial on Mandalas of Emotions
Secondary IDs:	

Study Status

Record Verification:	February 2020
Overall Status:	Completed
Study Start:	July 10, 2017 [Actual]
Primary Completion:	October 10, 2018 [Actual]
Study Completion:	December 1, 2018 [Actual]

Sponsor/Collaborators

Sponsor:	University of Campinas, Brazil
Responsible Party:	Principal Investigator Investigator: Gabriela Salim Spagnol [gspagnol] Official Title: Principal Investigator Affiliation: University of Campinas, Brazil
Collaborators:	Coordenação de Aperfeiçoamento de Pessoal de Nível Superior.

Oversight

U.S. FDA-regulated Drug:	No
U.S. FDA-regulated Device:	No
U.S. FDA IND/IDE:	No
Human Subjects Review:	Board Status: Approved Approval Number: 64276116400005404 Board Name: School of Medical Sciences Ethical Committee Board Affiliation: Comissão Nacional de Ética em Pesquisa (CONEP) Phone: (19) 3521-8936 Email: cep@fcm.unicamp.br Address: Universidade Estadual de Campinas (UNICAMP) Faculdade de Ciências Médicas (FCM)

	Comitê de Ética em Pesquisa (CEP) Rua: Tessália Vieira de Camargo, 126 Distrito de Barão Geraldo Campinas - SP CEP: 13083-887
Data Monitoring:	No
FDA Regulated Intervention:	No

Study Description

Brief Summary:	Epilepsy is a chronic disease with a psychosocial impact on the patient. The technique called 'Mandala of Emotions' (ME), derived from the Traditional Chinese Medicine, facilitates expression and awareness of emotions. In our pilot case study, the group "intervention with ME" managed to arouse their emotions and after the intervention felt lighter and relaxed at a higher frequency than the control group. We conducted a blind case control study to further assess usefulness of ME. Materials and Methods: Patients and caregivers recruited at an Epilepsy Outpatients Clinic with the approval of Ethics Committee were randomly divided into groups 'Control' (n=57) and 'Intervention' (n=53). In the ME group, five colored stones (green, red, yellow, white and black) were applied according to the emotion chosen by the participant. Individual assessment performed blinded to who received intervention applied a structured questionnaire and Likert-scales about the degree of relaxation and feelings pre- and post-experiment.
Detailed Description:	Patients and caregivers were recruited at an Epilepsy Outpatients Clinic. This study has approval of local Ethics Committee. Participants were invited to this research at the Outpatient clinic waiting room, and when they expressed interest, they were referred to the research team. Inclusion criteria for this study were: men and women treated in the epilepsy outpatient clinic, aged 18-60 years. Volunteers signed the informed consent to participate in the study, answered a questionnaire with information about demographics, epilepsy history (age of onset, frequency, last seizure, medications). They described their emotional characteristics (intuitive, emotive, and rational) and how they felt at that moment. They were invited to choose an emotion from a list (Concern/ obsession, Anger/irritation, Fear, Compassion, Sadness, Comprehension, Euphoria, Gratitude, Joy, Peace) to work on during the intervention. After, they were randomly divided into two groups: 'Control' and 'Intervention' (see Figure 1). The Mandalas of Emotions refers to five colors in accordance to the five stages or seasons (spring, summer, high summer, fall, winter). These establish a relation to the five functional systems (liver, heart, spleen and pancreas, lungs and kidney), and to five emotions (anger, joy/euphoria, concern/obsession, sadness/melancholy, fear) with its opposite correspondents (understanding, compassion, gratitude, enthusiasm, harmony) (Ling, 2013). Figure 1. Research procedures. The team, composed of five researchers, was divided in two groups: three researchers performed the interview before and after the intervention, two others applied the intervention, which divided participants in two groups: "control" and "intervention", assuming the confidentiality of this classification, as expected in a randomized, case control, blind assessment of outcome study. Both groups received the same initial recommendations: 'please, lie down, relax and pay attention to your breath'. The total procedure time was the same for both groups.

The intervention protocol was divided in two steps: first, patients spent 5 minutes in the phase of harmonization with five colored stones of a size of a walnut (green, red, yellow, white and black) placed around their bodies.

Second, in accordance to the emotion chosen by the participant, a matching mandala was placed next to the feet, on the abdomen, or next to the head depending on the self-perceived personality type, intuitive, emotive and rational for the remaining 10 minutes. The researcher also checked the control subjects once during the 15 fifteen minutes of experiment.

Soon after the experiment, individual assessment was performed blinded to who received intervention using a structured questionnaire and Likert-scales about the degree of relaxation and feelings.

Statistical analysis We first divided the groups and analyzed whether they differed in regard to sex, age, years of schooling, age of onset of seizures, time of last seizure, frequency of seizures per month, use of monotherapy and seizure control. Statistical analysis was conducted with SPSS using non-parametric tests (Mann-Whitney, ANOVA for repeated measures) and Chi-square. Content of patients perceptions were analyzed according to themes and compared between groups (control vs. intervention).

Conditions

Conditions:	Epilepsy
Keywords:	

Study Design

Study Type:	Interventional
Primary Purpose:	Treatment
Study Phase:	N/A
Interventional Study Model:	Parallel Assignment The team, composed of five researchers, was divided in two groups: three researchers performed the interview before and after the intervention, two others applied the intervention, which divided participants in two groups: "control" and "intervention", assuming the confidentiality of this classification, as expected in a randomized, case control, blind assessment of outcome study. Both groups received the same initial recommendations: ‘please, lie down, relax and pay attention to your breath’. The total procedure time was the same for both groups.
Number of Arms:	2
Masking:	Single (Investigator) The team, composed of five researchers, was divided in two groups: three researchers performed the interview before and after the intervention, two others applied the intervention, which divided participants in two groups: "control" and "intervention", assuming the confidentiality of this classification, as expected in a randomized, case control, blind assessment of outcome study. Both groups received the same initial recommendations: ‘please, lie down, relax and pay attention to your breath’. The total procedure time was the same for both groups.
Allocation:	Randomized
Enrollment:	110 [Actual]

Arms and Interventions

Arms	Assigned Interventions
Placebo Comparator: Control Participants received the instruction: 'please, lie down, relax and pay attention to your breath'. This procedure was carried during 15 minutes. Soon after the experiment, individual assessment was performed blinded to who received intervention using a structured questionnaire and Likert-scales about the degree of relaxation and feelings.	Behavioral: Control Participants were requested to "lie down, relax and pay attention to your breath".
Experimental: Intervention The intervention protocol was divided in two steps: first, patients spent 5 minutes in the phase of harmonization with five colored stones of a size of a walnut (green, red, yellow, white and black) placed around their bodies. Second, in accordance to the emotion chosen by the participant, a matching mandala was placed next to the feet, on the abdomen, or next to the head depending on the self-perceived personality type, intuitive, emotive and rational for the remaining 10 minutes (Figure 3B). The researcher also checked the control subjects once during the 15 fifteen minutes of experiment. Soon after the experiment, individual assessment was performed blinded to who received intervention using a structured questionnaire and Likert-scales about the degree of relaxation and feelings.	Behavioral: Mandalas of Emotions Application of mandalas during 15 minutes

Outcome Measures

Primary Outcome Measure:

1. Pre procedure Likert scale report
   Before the procedure, researchers asked "How are you feeling?" and participants replied in a Likert scale from 1-Very bad to 5-Very good.

   [Time Frame: 15 minutes]
2. Perception of changes after 5 min of procedure
   Five minutes after the procedure began, researchers applied the question: "How are you feeling?" and the researcher registered as they reported physical and emotional changes. No further measures or questionnaires were applied at this point.

   [Time Frame: 5 minutes]
3. Post procedure Likert scale report and qualitative questions
   After the procedure, researchers asked "How are you feeling?" and participants replied in a Likert scale from 1-Very bad to 5-Very good. Researchers also applied a questionnaire with these questions: "Did you experience body changes / retrieval of memories / retrieval of specific images? Do you have any observations regarding the procedure? Researchers registered yes/no reply and participants description of changes. No further measures or questionnaires were applied after this procedure.

   [Time Frame: 15 minutes]

Eligibility

Minimum Age:	18 Years
Maximum Age:	60 Years
Sex:	All
Gender Based:	No
Accepts Healthy Volunteers:	Yes
Criteria:	Inclusion Criteria: • men and women treated in the epilepsy outpatient clinic, aged 18-60 years. Volunteers signed the informed consent to participate in the study, answered a questionnaire with information about demographics, epilepsy history (age of onset, frequency, last seizure, medications). Exclusion Criteria: • Associated clinical conditions that prevented full comprehension of research procedures.

Contacts/Locations

Central Contact Person:	Li M Li, PhD Telephone: (19) 3521-9217 Email: limin@g.unicamp.br
Central Contact Backup:	
Study Officials:	
Locations:	**Brazil** Neuroimaging Laboratory Campinas, SP, Brazil, 13083-878 Contact: Li M Li, PhD (19) 3521-9217 limin@g.unicamp.br

IPDSharing

Plan to Share IPD:	No Individual participant data will not be shared.

References

Citations:	
Links:	
Available IPD/Information:	