Musical keyboard design for cognitivo-motor training in Alzheimer's Disease / Conception d'un clavier musical pour entraîner les fonctions motrices et cognitives dans la maladie d'Alzheimer

Mémoire

Sherezada Ochoa Echeverria

Maîtrise en sciences cliniques et biomédicales - avec mémoire
Maître ès sciences (M. Sc.)

Québec, Canada

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Sous la direction de :

Ernesto Morales, directeur de recherche
Cyril Schneider, codirecteur de recherche

Résumé

La maladie d'Alzheimer (MA) est la cause la plus fréquente de démence chez les personnes âgées. Un traitement n'a pas encore été trouvé, mais des études montrent que la combinaison de thérapies pharmacologiques et non pharmacologiques (TNP) peut ralentir la progression des symptômes de la maladie. Parmi les TNP, la thérapie musicale active ou musicothérapie active (TMA) a été largement utilisée. Cependant, cette approche requiert une supervision constante pour que la thérapie soit exécutée correctement. L'utilisation de technologies adaptées aux besoins des personnes avec MA pourrait alors leur permettre de participer de manière autonome aux sessions de TMA.

Ce mémoire de maîtrise s'organise autour de deux articles scientifiques. Le premier est une recension des écrits au sujet de la TMA utilisée en MA. Le deuxième article présente la démarche de co-conception d'un prototype du dispositif de clavier musical surdimensionné capable de guider les utilisateurs atteints de MA (stade léger) à travers des sessions de TMA qui comprennent des activités musicales, cognitives et motrices.

Des études complémentaires devront évaluer les effets de l'utilisation de ce dispositif musical sur les différents symptômes de la MA. Cependant, le matériau présenté dans le premier article de la thèse (recension des écrits) et les données en lien avec le deuxième article (co-conception), tels que les témoignages des participants au stage léger de la MA et les prototypes créés, indiquent que l'utilisation de ce clavier peut potentiellement atténuer les symptômes associés à la MA et ainsi améliorer la qualité de la vie de cette population.

Abstract

Alzheimer's disease (AD) is the most common cause of dementia in the elderly. A cure has not yet been found, but studies show that the combination of pharmacological and non-pharmacological therapies (NPT) can slow down the progression of the symptoms of the disease. Among the NPT, active music therapy (AMT) has been widely used to help relieve the symptoms of dementia. However, most AMT require constant supervision or guidance so that the person with AD can participate in the therapy session and perform it correctly. The use of technologies specifically designed to meet the needs of this population could allow them to autonomously participate in AMT sessions.

This master's thesis is organized into two articles, the first is a literature review regarding the application of AMT in AD. The second article presents the co-design process of an oversized musical keyboard that can guide users with mild AD through AMT sessions that integrate musical, cognitive and motor tasks. Further studies should evaluate the effects of using this device on different symptoms of Alzheimer's disease. However, the results presented in the first article of the thesis and the observations from the interactions between the participants (with mild AD) and the prototypes provided during the co-design process indicate that the use of this keyboard has the potential to alleviate symptoms related to AD and, thus, improve the quality of life.

Table des matières

Liste des figures et des tableaux

Liste des abréviations, sigles, acronymes

AD: Alzheimer's Disease

AMT: Active music therapy

BPSD: Behavioral and psychological symptoms of dementia

FG2: Researchers' focus group

HADS: Hospital Anxiety and Depression Scale

IRDPQ : Institut de réadaptation en déficience physique de Québec

MA: Maladie d'Alzheimer

MK1: Musical keyboard proposal 1

MK2: Musical keyboard proposal 2

MK3: Musical keyboard proposal 3

MT: Music therapy

NPT: Non-pharmacological therapies

PMT: Passive music therapy

TMA: Thérapie musicale active

TNP : Thérapies non pharmacologiques

TT1: Therapeutic tasks proposal 1

TT2: Therapeutic tasks proposal 2

TT3: Therapeutic tasks proposal 3

TT4: Therapeutic tasks proposal 4

TT5: Therapeutic tasks proposal

Avant-propos

Deux articles sont insérés dans le mémoire et ont été majoritairement rédigés par l'auteure du présent document sous la supervision de Dr Ernesto Morales, directeur de recherche et Dr Cyril Schneider, co-directeur de recherche. Les manuscrits 1 et 2 (chapitre 1 et 2) seront soumis dans les prochains mois aux revues « Physical & Occupational Therapy In Geriatrics » et « Disability and Rehabilitation: Assistive Technology » respectivement. Ils n'ont pas été modifiés pour répondre aux exigences du mémoire. Les références bibliographiques de chaque article sont listées à la fin de leur chapitre respectif. Les références du mémoire, c'est-à-dire de l'introduction jusqu'au chapitre 2, sont compilées dans une même liste située avant les annexes.

Ce projet n'aurait pu être accompli sans la contribution de nombreuses personnes qui m'ont permis d'approfondir ma réflexion au cours de mes démarches de recherche. Je remercie particulièrement mon directeur de recherche, M. Ernesto Morales et mon co-directeur de recherche, M. Cyril Schneider pour leur expertise et le temps investi à ce projet. Ils m'ont initiée au monde de la recherche scientifique, et leurs rétroactions constructives et questionnements m'ont permis de développer davantage la rigueur scientifique requise pour mener à terme un tel projet.

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Merci à mes parents et à ma sœur qui m’ont toujours offert leurs encouragements et qui m’ont permis de décompresser dans les moments difficiles. Mes derniers remerciements vont à mon mari, Juan Nino. Son amour, sa patience et sa grande implication dans mon projet m’ont permis de grandir comme personne et comme chercheure.

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Introduction

La maladie d'Alzheimer (MA) est la démence la plus commune (Alzheimer Association, 2018) et on estimait en 2015 que 46,8 millions de personnes dans le monde vivaient avec la MA et que son incidence devrait atteindre 131,5 millions d'ici 2050 (Prince et al., 2015). C'est donc un problème mondial qui va en augmentant.

La pathologie se caractérise par la dégradation des connexions neuronales et la mort neuronale au niveau cérébral (Cummings & Cole, 2002). La MA a généralement un stade initial amnésique qui peut durer plusieurs années avant que d'autres symptômes n'apparaissent (Perry & Hodges, 1999). Le déclin progressif de la mémoire et d'autres fonctions cognitives telles que le langage, l'attention, les performances visuospatiales, et les fonctions exécutives (Perry & Hodges, 1999) a un impact négatif sur la capacité d'effectuer des activités quotidiennes comme conduire vers un lieu connu, s'habiller ou suivre une recette de cuisine facile (Alzheimer Association, 2018).

La MA affecte également les émotions et les comportements; les personnes qui vivent avec cette démence se sentent souvent anxieuses, agitées ou déprimées. Elles peuvent aussi devenir désorientées dans le temps et dans l'espace et, au cours des phases ultérieures de la maladie, certaines personnes peuvent avoir des hallucinations (Lanctôt et al., 2017).

La MA a également un impact sur l'état émotionnel, la santé et l'économie des proches aidants et des membres de la famille (Alzheimer Association, 2018). Une majorité de personnes avec cette maladie ne peuvent plus travailler et ont besoin de soins constants (Wong, Gilmour, & Ramage-Morin, 2016). Ceci se traduit par des coûts élevés pour les systèmes de santé et la société en général (Association, 2018; Jia et al., 2018).

Il n'existe actuellement aucun traitement pour la MA. Les approches thérapeutiques visent souvent à améliorer la qualité de vie ou à réduire les symptômes associés (Alzheimer Association, 2018). Les interventions pharmacologiques comme l'utilisation d'inhibiteurs de la cholinestérase et d'antipsychotiques (car il est montré que les circuits cholinergiques sont hypoactifs) ont une capacité limitée à améliorer les symptômes de la démence par elles-mêmes (Wang et al., 2015).

L'effet limité des médicaments sur la maladie a suscité un intérêt croissant pour les thérapies non pharmacologiques (TNP) visant à maintenir, à compenser et à améliorer les capacités mentales des personnes atteintes de MA (Olazarán et al., 2010). Les essais de traitements actuels combinent donc des approches pharmacologiques et non pharmacologiques (Olazarán et al., 2010).

Le terme TNP désigne les approches qui obtiennent des résultats cliniques chez les personnes avec la maladie ou chez les personnes autour d'eux sans l'utilisation de médicaments. L'intérêt croissant de l'utilisation des TNP dans la MA a permis de démontrer l'utilité de prendre avantage des capacités préservées dans cette maladie pour optimiser ceux qui ont été affectés (Baird, Umback & Thompson, 2017; Benigas & Bourgeois, 2016; Van Halteren-Van Tilborg, Scherder, & Hulstijn, 2007).

Parmi les TNP, la musicothérapie a été largement utilisée pour aider à soulager les symptômes de démence, et de nouvelles études concernant son utilisation ont été encouragées (Guétin et al., 2009; McDermott, Crellin, Ridder, & Orrell, 2013; Olazarán et al., 2010; Simmons-Stern, Budson, & Ally, 2010). Cette TNP est si remarquable parce que les structures cérébrales reliées à la perception et la reconnaissance de la musique sont épargnées dans la MA (Matrone & Brattico, 2015).

Le terme musicothérapie fait référence à l'utilisation de musique et/ou d'éléments musicaux pour développer ou restaurer des fonctions chez une personne et améliorer ainsi sa qualité de vie (Darnley-Smith & Patey, 2003). Bien que les modalités actif (TMA) et passif (TMP, écoute de la musique) de la musicothérapie aient été trouvées capables de soulager les symptômes de la MA, il a été suggéré que la TMA pouvait avoir des effets bénéfiques plus importants que la TMP (Raglio et al., 2013; Sakamoto, Ando & Tsutou et al., 2013). TMA fait référence à l'implication active de la personne dans la création musicale lors des séances thérapeutiques musicales (Darnley-Smith & Patey, 2003).

Durant les sessions de TMA, le participant avec MA doit être guidé et accompagné par un thérapeute ou un proche aidant afin qu'il puisse participer à la séance thérapeutique et l'effectuer correctement (Mathews, Clair, & Kosloski, 2001). Cela peut poser un problème pour les personnes qui n'ont pas d'accès à un thérapeute régulier ou qui souhaitent poursuivre des TNP réalisables à la maison.

Bien que certaines interfaces thérapeutiques aient été développées pour être utilisées à domicile, beaucoup d'entre elles requièrent des plateformes technologiques qui demandent des connaissances et une dextérité numérique que les personnes âgées n'ont généralement pas (Aurilla & Arntzen, 2011; Imbeault, Bouchard, & Bouzouane, 2011), comme par exemple l'utilisation d'un ordinateur ou de consoles de jeux vidéo (Boulay, Benveniste, Boespflug, Jouvelot, & Rigaud, 2011; Imbeault et al., 2011). À cet égard, il est suggéré que les personnes vivant avec la MA puissent bénéficier de la musicothérapie grâce à l'utilisation d'une technologie spécialement conçue pour répondre à leurs besoins (Lancioni et al., 2019). Cette technologie pourrait atténuer ou retarder la progression des symptômes de la MA, ce qui améliorerait leur qualité de vie.

Objectifs principal et spécifiques

Ce mémoire a pour principal objectif de proposer un dispositif musical électronique permettant aux personnes au stage léger de la MA de s'engager de manière autonome dans des sessions de TMA.

Pour y arriver, cinq objectifs spécifiques ont été poursuivis :

1. Documenter les effets bénéfiques de la TMA sur les symptômes de la MA.
2. Indiquer les mécanismes neuronaux potentiels sous-jacents aux effets bénéfiques de la TMA sur les symptômes de la MA.

3. Décrire les conditions favorisant la participation des personnes atteintes de MA dans la TMA.

4. Repérer les différentes approches utilisées pour susciter une participation autonome des personnes atteintes de MA à l'utilisation de dispositifs électroniques.

5. Co-concevoir un dispositif musical électronique qui favorise la TMA autonome des personnes au stade léger de la MA.

Le chapitre 1 répond aux quatre premiers objectifs spécifiques par le biais d'une recension des écrits sur l'utilisation de la TMA auprès de la population atteinte de MA. La recension des écrits propose des recommandations pour le développement de sessions de TMA qui peuvent, ou non, inclure des dispositifs technologiques. Le chapitre 1 aborde également les thèmes de l'efficacité rapportée de la TMA sur les symptômes de la MA et sur le cerveau avec MA, les stratégies d'intervention en lien avec la TMA pour traiter la MA, et l'utilisation d'appareils technologiques pour la participation active à la TMA.

Le chapitre 2 adresse le cinquième objectif spécifique. Il présente la démarche de co-conception d'un dispositif musical qui aide les utilisateurs atteints de MA légère à utiliser la TMA de manière autonome. Cette co-conception est basée sur les données et recommandations du chapitre 1. De plus, le processus de co-conception inclut des sessions de rencontres individuelles avec des personnes avec la MA (stade léger) et des sessions de co-conception en groupe avec des chercheurs.

Chapitre 1. Active Music Therapy for People with Alzheimer's Disease: A Literature Review

1.1 Résumé

Cet article présente une recension des écrits sur l'utilisation de la musicothérapie active (TMA) en tant qu'approche thérapeutique pour traiter la maladie d'Alzheimer (MA). Il commence par présenter l'étiologie et l'évolution de la MA. Ensuite, les effets de la TMA sur les symptômes de cette démence sont documentés. Après, les mécanismes neuronaux potentiels sous-jacents de la TMA sur les symptômes de la MA sont indiqués. Enfin, les pratiques recommandées d'utilisation de la TMA chez la population avec MA sont identifiées. Les données présentées indiquent une relation entre la TMA et l'amélioration des symptômes cognitifs et neuropsychiatriques dans la MA. Cependant, une absence d'effets bénéfiques sur l'autonomie fonctionnelle est aussi remarquée. Les recommandations mentionnées dans la dernière section font allusion à cela et à d'autres préoccupations lors de la conception de la TMA pour la population avec MA.

1.2 Abstract

This article presents a literature review concerning the use of Active Music Therapy (AMT) as a therapeutic approach to treat Alzheimer's Disease (AD). It begins by presenting the etiology and course of AD followed by the effects of AMT over the symptoms of this dementia. Then, it elaborates on the potential underlying neural mechanisms of AMT over the brain with AD. Subsequently, recommended practices of AMT usage on the AD population are identified. Data presented indicates a clear relationship between AMT and the improvement of cognitive and neuropsychiatric symptoms in AD. However, it also reveals a lack of beneficial effects over the functional sphere of this dementia. Recommendations pointed out in the last section allude to this and other concerns when designing AMT for the AD population.

1.3 Introduction

Alzheimer's Disease (AD) is a neurodegenerative disorder and its precise cause is still under research. Current therapeutic approaches include Pharmacological and

Non-Pharmacological interventions (NPT) (Chalfont, Milligan, & Simpson, 2018). Pharmacological interventions (e.g., the use of cholinesterase inhibitors and antipsychotics) have limited capacity to improve dementia symptoms by themselves (Wang et al., 2015). Consequently, it is recommended that they are combined with non-pharmacological approaches (NPT) to have a greater influence over the disease's symptoms (Olazarán et al., 2010).

Some popular NPT are music therapy (MT) cognitive-based therapies, art therapy, movement therapy, and psychosocial therapies (Douglas, James, & Ballard, 2004; Gardette, Coley, & Andrieu, 2010). Among these, music therapy has been widely used to help alleviate dementia symptoms, and further studies regarding its use have been encouraged (Guétin et al., 2009; McDermott, Crellin, Ridder, & Orrell, 2013; Olazarán et al., 2010; Simmons-Stern, Budson, & Ally, 2010).

Music's therapeutic advantages have been used worldwide and in various times and cultures (Darnley-Smith & Patey, 2003). Its use comes from the fact that music is fundamental for us humans; ever since we are born, we use musical qualities to communicate with others (i.e., voice intensity, melody, pitch, etc.) (Darnley-Smith & Patey, 2003). The underlying mechanisms that contribute to music's therapeutic effects are not fully understood but they are believed to modulate emotion, attention, cognition, behavior, and communication (Koelsch, 2009).

The term MT refers to the use of music and/or musical elements (such as rhythm) for therapeutic purposes (Darnley-Smith & Patey, 2003). MT aims to develop or restore functions in a person to consequently improve their quality of life (Darnley-Smith & Patey, 2003). Music therapists are typically musicians who have undergone training in using music to accomplish therapeutic aims. However, even in the absence of a professional music therapist, music is used to alleviate health problematics in patients by many clinicians and caregivers (Sakamoto, Ando, & Tsutou, 2013).

During music therapeutic sessions, participants can play an active or passive role. In passive music therapy (PMT), techniques such as listening to music are used. In contrast, active music therapy (AMT) requires the participants to be actively involved in the production of music (such as by playing an instrument, singing or clapping) (Darnley-Smith & Patey, 2003).

Several experiments have demonstrated that PMT has a positive impact in AD on aspects such as stress (Sakamoto et al., 2013) anxiety, depression (Guétin et al., 2009), autobiographical memory (El Haj, Clément, Fasotti, & Allain, 2013; Foster & Valentine, 2001), and over language limitations (El Haj, Fasotti, & Allain, 2012). However, it has been suggested that AMT can have stronger beneficial effects reducing these and other dementia related symptoms (Raglio et al., 2013; Sakamoto et al., 2013).

For instance, Sakamoto and colleagues (2013) found that AMT can enhance the emotional state (measured with the faces scale) more than passive music therapy. It has also been found that while both PMT and AMT are able to reduce affective disturbance, anxiety, and phobias, AMT is also able to reduce other behavioral and psychological symptoms of dementia such as paranoid and delusional ideation, aggressiveness, and activity disturbance (Sakamoto et al., 2013; Svansdottir & Snaedal, 2006).

Furthermore, because AMT requires the senior's physical engagement in rhythm-based movements it can contribute to the improvement of fine and gross motor skills, slowing down sensorimotor decline, or, enhancing mobility and coordination (Touchon et al., 2012). This is relevant because decline in psychomotor skills such as coordination, speed, and perceptual integrative abilities (typical in AD) interfere with the autonomy that seniors have (Bailon, Roussel, Boucart, Krystkowiak, & Godefroy, 2010; Hellen, 1998).

Due to its prevalence and reported effects, it seems that AMT is widely considered as a potential NPT for people with AD to help treat their disease-related symptoms. Despite the many reviews focused on music interventions, to our knowledge, literature reviews focused particularly on Active Music Therapy have not yet been developed. The purpose of this literature review is thus to document the beneficial effects of AMT in AD, as well as the facilitators, modalities, and recommendations on how to administer it.

In the succeeding paragraphs, the etiology and course of AD will be introduced, followed by the impact of AMT over cognitive-motor function, over behavioral and neuropsychiatric symptoms, and over functional autonomy in AD. Subsequently, the potential neural mechanisms underlying these effects will be discussed. Finally, a section gathering recommendations on how to administer AMT will be presented including facilitators, modalities, and the usage of electronic devices to facilitate an autonomous participation.

1.4 Methodology

The literature review was written following the guidelines given by the University of Toronto (Skene, n.d.) and the University of Massachusetts (Mongan-Rallis, 2018). Bibliographical search was done over a period of two years. It was conducted periodically (every three months) over the two years to ensure that the most recent articles were also considered for the literature review. The search was made in the search engines Google Scholar, database PubMed, Cochrane Library, CINAHL, Mendeley, PsycINFO and SciELO.

The search was done for studies regarding the following categories : etiology and the course of Alzheimer's Disease, the course of AD over brain structures, the use of Non Pharmacological Therapies in AD, music therapy, music therapy used to treat AD and other dementias, active music therapy in AD, instrument playing, technological devices for active music therapy in AD and related dementias, physical activity's effect over AD, and cognitive therapy in AD. No specific query was used to retrieve the articles.

First, relevant studies were selected by screening of their title. Then, the abstract and the body of the selected studies were overviewed to get a general idea of the content (Mongan-Rallis, 2018). In addition, bibliographical references of the resulting articles were also searched to identify other relevant publications that were not drawn trough the strategic search.

The Mendeley Desktop (version 1.19.4) reference manager was used to organize and annotate the selected articles. The articles were grouped into the categories of their retrieval (Mongan-Rallis, 2018). They were then reviewed and annotated. Revision of the literature consisted on analyzing if the evidence presented by each document supported their conclusion, if all the articles arrived at the same conclusion, and if not, reasons why this could be (Mongan-Rallis, 2018; Skene, n.d.). Patterns among articles were identified and synthesized into annotations (Mongan-Rallis, 2018; Skene, n.d.). Strengths and limitations of the studies, and the questions that were raised by the literature were also reflected on (Mongan-Rallis, 2018; Skene, n.d.).

The information retrieved by the literature review was summarized into a word document. This document and the previously taken notes were used to develop the literature review, which consists in the introduction, the body of the article and the conclusion (Mongan-Rallis, 2018; Skene, n.d.).

1.5 Etiology and Course of Alzheimer's Disease

While the precise cause of Alzheimer's Disease type dementia is unknown, it has been found to be a multifactorial disorder in terms of its risk factors (Reitz & Mayeux, 2014; Rovio et al., 2005; Stern et al., 1994). Genetics, cardiovascular diseases, smoking, body weight and intellectual activity are just a couple of the many circumstances that can influence the manifestation and development of this neurological disorder (Reitz & Mayeux, 2014).

Some ongoing brain affections that have been identified in this disease are a disintegration of the tau protein, a decrease of glucose metabolism, and an accumulation of amyloid beta plaques between neurons (Cummings & Cole, 2002; Mouiha & Duchesne, 2012). These set of events alter neural and synaptic function and eventually lead to neuronal death (cortical atrophy) (Cummings & Cole, 2002; De Meyer et al., 2010; Nagele et al., 2004); this is reflected in a progressive decrease of brain volume (Thies & Bleiler, 2011).

Brain changes start at a preclinical stage of the disease, i.e., before any cognitive symptoms (such as the initial memory loss) are detected (Belleville, Fouquet, Duchesne, Collins, & Hudon, 2014; De Meyer et al., 2010). The mild, moderate, and severe stages of the disease are characterized by an ongoing decline in brain function (Thies & Bleiler, 2011).

While the intensity of the effects varies over time, they include a decline in the cognitive, motor, behavioral and neuropsychiatric spheres (Thies & Bleiler, 2011). This gradually impacts the functional autonomy of the seniors (the ability to perform day to day activities such as meal preparation, bathing ad shopping) and isolates them from their past social participation in life.

Mild AD

In early stages, cortical atrophy has begun in brain areas related to learning and memory (medial temporal lobe), and thinking and planning (frontal and prefrontal cortex) (Convit et al., 2000; McDonald et al., 2009). Among these areas, the hippocampus, a part of the brain essential in forming memories, appears to be one of the first brain structures affected (Mouiha & Duchesne, 2012). Thus, the capacity to form new memories becomes impaired in this population (Thies & Bleiler, 2011).

Other initial symptoms of AD vary from person to person, but cognitive and motor symptoms include a decline in word finding, a reduced reasoning and judgment capacity and visuospatial issues (i.e., deficits in spatial judgment, visual discrimination and orientation) (Cummings & Cole, 2002; Quental, Brucki & Bueno, 2009). Behavioral and Psychological Symptoms of Dementia (BPSD) in this stage mostly consist on agitation and anxiety (Cummings & Cole, 2002; Thies & Bleiler, 2011). These BPSD are greatly because many seniors are aware of their diminished capacities to cope with daily tasks such as their increasing difficulties to communicate orally.

Moderate AD

As the disease progresses, the damage worsens and advances to brain areas that control language (temporal cortex), reasoning, sensory processing, and conscious thought (McDonald et al., 2009). Additionally, the ability to learn, plan, coordinate, and execute multi-step tasks or cope with new situations is compromised (Thies & Bleiler, 2011).

The impairments experienced at this stage begin to interfere with professional and social life. People often have difficulty organizing their thoughts, and many might start struggling to recognize family and friends (Thies & Bleiler, 2011). However, emotional functioning (i.e., the ability to recognize emotional prosody and different emotions) in this and the advanced stage of the disorder is relatively preserved relative to the general cognitive state (Bucks & Radford, 2004).

At the end of this stage, BPSD worsen, and cognitive and behavioral symptoms start to overlap (Thies & Bleiler, 2011). In this stage seniors often show personality changes such as the abandonment of activities and hobbies that they used to consider important and desirable (Lanctôt et al., 2017). They refuse to participate because they fear they will fail or just because they are depressed (Di Domenico, Palumbo, Fairfield & Mammarella, 2016).

Severe AD

By this stage, most of the cortex is seriously affected, and brain tissue has shrunk considerably (Thies & Bleiler, 2011). Neuropsychiatric manifestations (BPSD) such as psychosis, agitation, apathy, depression, and sleep disturbances are typical (Lanctôt et al., 2017). Other symptoms of this stage include severe communication impairments, greater difficulty or impairment to recognize loved ones, loss of environmental awareness, and independence for personal care. Near the end of their life, people often stay in bed most of the time as their body control shuts down (Thies & Bleiler, 2011).

1.6 Influence of Active Music Therapy over AD Symptoms

Effects over Cognitive-Motor Function

AMT has shown to have a positive effect over cognition. Studies have found an improvement on memory, on orientation capacity (Gómez Gallego & Gómez García, 2017), on language (Zhang et al., 2018), on psychomotor skills (Kida et al., 2015), and on general cognitive state (Wang et al., 2018) related to AMT in participants at different stages of the disease.

For instance, Wang and colleagues (2018), found that a three-month singing intervention had a significant beneficial impact over the general cognitive state of participants. Moreover, they found that these results were still significant after a three-month follow-up measurement.

In a three-week intervention where participants were encouraged to accompany music by playing instruments, doing rhythmic movements, dancing, and guessing the name of songs, Gómez Gallego and Gómez García (2017) found that participants at mild and moderate stages of the disease progressively improved their orientation and memory functions. Furthermore, they found a significant improvement of language in people at the moderate stage.

In a different study, Zhang and colleagues (2018) found that group singing was also able to enhance language in patients with mild AD and that this effect was maintained up to three months after the intervention was completed. In another intervention (Kida et al., 2015) that consisted of group and individual singing sessions with a karaoke device for six months, results showed that AMT with singing also leads to improvement in psychomotor speed (ability to detect and respond to rapid environmental stimulus or changes).

In fact, during the singing with a karaoke study (Kida et al., 2015), researchers also assessed the activation of brain regions with fMRI during a karaoke task before and after the intervention. They found that the after-minus-before calculation revealed a reduction of activity in the left-lingual and right angular gyrus; this suggests that after the six-month intervention participants performed the same task with a smaller activation of these brain regions than before. The authors thus suggest that the patients acquired new cognitive strategies for karaoke singing.

Effects on Behavioral and Neuropsychiatric Symptoms

In the same study of Kida et al. (2015), results based on interviewing caregivers about the daily lives of the patients before and after the singing intervention, found a significant decrease in the Neuropsychiatric Inventory score (NPI, an inventory to assess behavioral functioning). This suggests that behavioral and psychological symptoms of the participants improved with the intervention. Furthermore, the intervention also resulted in a prolongation of the seniors' sleep. Accordingly, it has also been found that symptoms such as depression and appetite disorders can be benefited with an AMT approach (Giovagnoli et al., 2018).

Similar results regarding NPI scores were obtained by Wang et al. (2018). They analyzed the effects that a three-month singing intervention had over the cognitive function of seniors with mild AD who were already receiving pharmacological treatment. NPI scores were significantly lower at the end of the treatment and even over a three-month follow-up than in the baseline measurement. This indicates that music therapy can be effective to support pharmacological intervention in AD. In addition, a study made by Prattini (2016) with seniors with middle stage to late-stage AD, found that verbal participation (i.e., singing, humming, whistling) during the MT session correlated to lower levels of agitation, and that overall, AMT helped reduce verbally agitated behaviors.

In the same study previously mentioned of Gómez Gallego and Gómez García (2017), the results from the Hospital Anxiety and Depression Scale (HADS) indicated that music therapy had a positive effect on anxiety and depression in people with mild and moderate stages of AD. These results were further supported with results in the NPI, indicating that anxiety improved significantly in the mild dementia group, while improvements were less marked in the group with moderate dementia. NPI results also showed that the AMT decreased problematics such as delusions, hallucinations, irritability, and agitation in the group with moderate dementia, probably due to the higher intensity of their symptoms. However, they found that depression did not improve significantly in patients with moderate dementia and lessened only slightly in those with mild dementia.

Effects on Functional Autonomy

Findings from the three-week AMT intervention program of Gómez Gallego and Gómez García (2017) found that, despite changes in patients' behavior, no impact was found on functional dependence after the intervention. In line with the previous results, an experiment (Zhang et al., 2018) in which participants with different stages of AD participated in singing sessions for three months found no significant effect over the scale activities of daily living (functional status). In fact, in Kida and colleagues' intervention (2015), findings suggested that functional ability in daily activities had decreased. This was reflected in a decrease on the Barthel Index and in the Disability Assessment for Dementia scores (both assess functional independence).

1.7 Potential Neural Mechanisms underlying AMT's After-Effects in AD

AMT is known to have a wide range of physiological effects on the human body including changes in heart rate, breathing, blood pressure, skin conductivity, skin temperature, muscle tension, and biochemical responses (Kreutz, Murcia, & Bongard, 2012). It is also known to have beneficial effects over the most affected brain structures and circuits in Alzheimer's Disease.

Influence on Emotions

Music has the power to create an emotional involvement (García et al., 2012) and to improve the emotional state of its listeners (Sakamoto et al., 2013). It has been found to modulate brain activity in the limbic and paralimbic cerebral structures (Koelsch, 2005); these structures are involved in emotion processing in response to music (Koelsch, 2005).

Blood and Zatorre (2001) found that listening to pleasurable music can make activity changes in central structures of the limbic system such as the hypothalamus and the amygdala. The modulation of this core structure for emotion processing (amygdala) could help explain why emotional symptoms of people with AD improve with musical therapy.

It is known that listening to one's favorite music (PMT) can decrease anxiety and cortisol levels (biomarkers of stress), and promote relaxation (Chlan, 1998). Interestingly, AMT has been found to further increase the parasympathetic nervous system's activity (Sakamoto et al., 2013) following the AMT sessions, evoking stronger positive emotions and reducing stress. This was found in spite of AMT requiring an active participation (clapping, singing, and dancing).

Influence on Memory Loss

While memory loss is one of the most evident symptoms of AD, it has been found that music training has a positive impact over brain areas involved in this impairment (Chen, Penhune, & Zatorre, 2008; Herdener et al., 2010).

During memory consolidation (long term-potentiation) the hippocampus and the prefrontal cortex play an essential role; the hippocampus contributes to fix, and replay memories and the prefrontal cortex helps ensure the contextual meaningfulness of all related memories (Preston & Eichenbaum, 2013). In AD, long-term potentiation undergoes a gradual deterioration affecting these two structures (Chen, Kagan, Hirajura & Xie, 2000).

The emotional involvement created by music favors the retrieval of memories (García et al., 2012). This has been explained by the importance of the emotional factor needed for memory consolidation (García et al., 2012) and by the involvement of limbic and paralimbic cerebral structures (such as the hippocampus and amygdala) during the processing of emotion evoking music (Koelsch, 2005). Furthermore, the repetition of motifs in music making activates both the prefrontal cortex and the hippocampus (Burunat, Alluri, Toiviainen, Numminen, & Brattico, 2014).

In this respect, it has also been found that aural musical training activates the hippocampus (Herdener et al., 2010), whose volume decreases with the severity of AD (Devanand et al., 2007; Wang et al., 2003). It is thus believed that such reactivation of atrophied hippocampus' cells by musical training can enhance cognitive abilities such as memory (Groussard et al., 2010).

Another feature of AD is a reduced working memory capacity. In order to interpret a piece using a musical instrument, AMT engages working memory to modulate rhythm, timing, and sequences. Working memory belongs to higher cognitive functions and also requires the activation of the prefrontal cortex (Chen et al., 2008). The atrophy of the prefrontal cortex in AD explains in part the memory issues, and its reactivation during AMT explains the positive after-effects on working memory.

In addition, during AMT, motor activity generates sensory information that is sent to the brain; thus, concurrent activation of sensory (perception) and motor cortices (action) may influence neural plasticity within the hippocampus (memory) and countervail the neurochemical and synaptic changes related to the progressive loss of hippocampal function in AD (Intlekofer & Cotman, 2013; Kim et al., 2014; van Praag, Kempermann, & Gage, 1999).

In fact, evidence suggests that physical exercises often utilized in AMT (Cevasco & Grant, 2003), reinstate hippocampal function (Scharfman et al., 2005) by an influence on the expression of brain-derived neurotrophic factor (BDNF) and other factors promoting growth, survival, and neural function (Intlekofer & Cotman, 2013; Kim et al., 2014).

Influence on Oral Communication

The potential of AMT to improve speed and language abilities in AD relies on its further influence on different structures. Of note, language function is not circumscribed to left peri-sylvian areas and insula, but rather engages widespread networks connecting prefrontal-parietal-temporal structures. Thus, memory and speech function are intertwined in these networks, and working memory deficits in early-onset AD participate in speech impairment (Olichney et al., 2010; Stopford, Thompson, Neary, Richardson, & Snowden, 2012). Indeed, in addition to memory deficits, the frontal lobe pathology in AD reduces the semantic details, the spanning capacity, the attention, the search and retrieval functions, all influencing the speech function (Almor, Kempler, MacDonald, Andersen, & Tyler, 1999; Bayles, 2003).

Reactivation of prefrontal cortex by AMT (see the section “influence on memory loss”) could then explain the recovery of speech in AD. Also, progressive expressive aphasia, altered speech articulation and semantic memory issues found in mild AD could result from the hypometabolism and atrophy of the left insular cortex (Ackermann & Riecker, 2004; Bonthius, Solodkin, & Van Hoesen, 2005; Nestor et al., 2003; Rosen et al., 2004) and from the atrophy of the left superior temporal areas (Harasty, Halliday, Kril, & Code, 1999). However, these language disorders could be compensated by the activation of superior temporal areas by AMT activities, i.e., melody discrimination tasks, rhythm synchronization when playing an instrument or dance imitation (Karpati, Giacosa, Foster, Penhune, & Hyde, 2016), and by the increase of regional cerebral blood flow in the insula and the ventral medial prefrontal cortex by the pleasurable music listening experience (Blood & Zatorre, 2001).

1.8 Recommended Practices for AMT Design

The present literature review has presented some beneficial effects of AMT in AD based on symptoms’ reduction along with neural significance. The following section will help point out specific recommendations for the use of AMT in AD. At the end of this section a summary of these recommended practices will be presented (see table 1).

AMT Modalities and their Influence over the Patient’s Involvement

The type of music and specific songs or melodies used during AMT have shown to have an impact on the outcome of the participation in AMT sessions (Cevasco & Grant, 2003). To examine the optimal means to elicit participation in AMT, Cevasco and Grant (2003) examined four intervention modalities (exercise to vocal music, exercise to instrumental music, exercise with instruments to vocal music, and exercise with instruments to instrumental music). They found that exercise to instrumental music results in more participation than to vocal music and that exercise with instruments to vocal music. Furthermore, the results indicated that exercise with instruments to instrumental music resulted in more participation than exercise with instruments to vocal music.

The authors suggest that some seniors with AD cannot discriminate between the verbal stimuli of the song and the vocal cues of the therapist. In fact, during the study, Cevasco and Grant (2003) assure that many clients stopped participating in the designated task (exercise movements) but sang along with vocal music. This is particularly relevant because static posture is affected during cognitive tasks in people with AD (Manckoundia, Pfitzenmeyer, d'Athis, Dubost, & Mourey, 2006). It is thus important that vocal reminders indicating adequate posture and movements be correctly discriminated from vocal music to avoid any participants from falling.

Recommendation 1
To elicit positive participation and promote engagement, playing an instrument (by the senior with AD) to a musical piece should be chosen before other modalities of musical activity (such as improvisation) (Cevasco & Grant, 2003).

Recommendation 2
When implementing a verbal cue-oriented activity, choose instrumental music over vocal to avoid confusion between the verbal stimuli of the song and the vocal cues of the therapist (Cevasco & Grant, 2003).

Regarding the use of instruments to elicit participation in seniors with AD, Brotons and Pickett-Cooper (1994) found similar results. They evaluated the preferences of AD people for different music activities (singing, instrument use, dance/movement, games, and composition/improvisation). All patients participated in all types of music activities and verbally said to enjoy them equally; however, they spent significantly more time playing instruments, dancing, and playing games than improvising and composing. They attributed this result to the fact that particularly, playing instruments and dancing were activities highly structured with a minimum of instructions and did not require spontaneity because a model was continuously being demonstrated.

Similar results to those from Brotons and Pickett-Cooper (1994) were found in a different study (Hanson, Gfeller, Woodworth, Swanson, & Garand, 1996) that compared the effectiveness of three different types of music activities (movement, rhythm, and singing) for people with AD and related disorders. Their results indicated that all participants showed a significantly greater amount of participation during movement activities than during singing activities. They state that a greater amount of passivity was found during singing activities than during movement ones.

Despite the effectiveness of each type of active music activity to elicit participation, it is important that music sessions have a varied repertoire of activities to stimulate patients' needs and interests. Furthermore, these activities should be adapted on the spot based on the participants' needs (Brotons & Pickett-Cooper, 1994).

Recommendation 3
Musical activities such as dancing, playing an instrument, and playing musical games are enjoyed by people with AD. To promote engagement in the therapy, a variety of these AMT activities that include minimum and simple instructions should be included (Brotons & Pickett-Cooper, 1994).

Recommendation 4
AMT activities should be flexible and able to adapt to each participants' needs (Brotons & Pickett-Cooper, 1994).

In fact, another important reason has been given for AMT to include different activities. As mentioned previously, studies have found that AMT might not yield any improvements in functional autonomy in AD because this neurological disorder is multifactorial in terms of its risk factors (Reitz & Mayeux, 2014; Rovio et al., 2005; Stern et al., 1994). It has been thus recommended that activities should contain more than one nature of intervention (i.e., cognitive, motor) to synergistically impact all symptoms of the disease (Chalfont et al., 2018; Karp et al., 2006).

A multimodal approach such as an AMT intervention with cognitive-motor activities has previously been suggested to lead to clinically significant effects on global function (Gómez Gallego & Gómez García, 2017; Ngandu et al., 2015). Likewise, it has been mentioned that music therapy sessions that simultaneously stimulate motor and cognitive components of global function in AD should improve motor function, reduce functional limitations and thus prevent early institutionalization (Arkin, 2007; Chalfont, et al., 2018; de Melo Coelho et al., 2012; Heyn, 2003).

An example of such multimodal approach could be individualized piano training. In addition to being an engaging instrument for the elderly (Boulay, Benveniste, Boespflug, Jouvelot, & Rigaud, 2011), music training with this instrument has shown to enable the generalization of cognitive gains over daily activities better than other therapies that use a unimodal training task (Bugos, Perlstein, McCrae, Brophy, & Bedenbaugh, 2007). For instance, it can improve the executive function, perceptual speed, and visual scanning which are often impaired in AD (Bugos et al., 2007). This can be explained because of the multimodal skills required to play a musical instrument (Bugos et al., 2007); to play, one needs to plan, organize, and sequence musical passages (Bugos et al., 2007), to integrate different sensory modalities (visual, auditory, proprioceptive), and to involve the sensorimotor system for perception and action (Lappe, Herholz, Trainor, & Pantev, 2008).

A specific cognitive technique that can also be implemented in music activities is spaced retrieval. This memory training technique is often used to enhance or regain functional autonomy in AD (Benigas & Bourgeois, 2016; Creighton, Davison, van der Ploeg, Camp, & O'Connor, 2015) such as in using walking aids (Creighton, et al., 2015) and swallowing (Benigas & Bourgeois, 2016). The spaced retrieval technique helps people with AD learn and retain important information by taking advantage of their implicit memory system which is spared in this disease (Van Halteren-Van Tilborg, Scherder, & Hulstijn, 2007). It uses procedural memory (a form of implicit memory) to recall information over progressively longer time intervals (Benigas & Bourgeois, 2016).

The fact that implicit memory is spared means that seniors with AD are well able to learn tasks over practice (Baird, Umback & Thompson, 2017; Benigas & Bourgeois, 2016). In fact, the ability of non musicians with AD to learn a new song (learning and recall in the form of singing) is preserved even in the severe stage of the disease (Baird et al., 2017). The spaced retrieval technique could be implemented in AMT activities in addition to motor tasks such as upper body rhythmic movements to promote the learning of short melodies on a musical instrument.

In addition to promoting functional autonomy, utilizing a multimodal approach can also engage people with AD in the maintenance or learning of beneficial activities that they would otherwise not want to practice, such as in doing physical exercise (Cevasco & Grant, 2003).

Recommendation 5

To synergistically impact all symptoms of AD, AMT activities should contain cognitive, motor, and musical tasks (Gómez Gallego & Gómez García, 2017; Ngandu et al., 2015).

Recommendation 6

Multimodal tasks that include pleasurable activities for the participant can be used to promote the engagement in activities (also included in the multimodal task) in which they would not voluntarily participate but that are helpful treating the disease (Cevasco & Grant, 2003).

Recommendation 7

The space retrieval technique can be used to teach people with AD new tasks (Benigas & Bourgeois, 2016; Creighton et al., 2015).

Use of Electronic Interfaces: Facilitators for an Autonomous Therapy

The use of electronic interfaces for AMT has been suggested as a viable option to complement other interventions (Kida et al., 2015), and to allow seniors to self-regulate their musical stimulation (Lancioni, Singh et al., 2013; Lancioni et al., 2019).

Such is the example of an electronic musical game that uses a touch screen interface to control a system that utilises chords to create music (Riley, Alm & Newell, 2009). While this game was not targeted specifically to AD users it was thought for and tested in people with different dementias. This game uses a tablet to be played and was aimed to be used without the need for prior musical or instrumental experience. The game was named “ExPress Play” (Riley et al., 2009).

ExPress Play is a system that aims to enable people with dementia to create music (Riley et al., 2009). It has a polished visual display; the creators aimed for it to be aesthetically pleasing because this is partly responsible for engaging the user (Riley et al., 2009). The screen is placed horizontally on a table and slightly inclined in front of the user. Buttons allowing the user to play music specific to happy, sad, and angry moods are placed on the bottom part of the screen. The system emits pleasant sounding music regardless of what the user plays. The emitted sound varies depending on the area of the screen that is being touched (i.e., moving down the screen causes pitch to become lower).

Usability testing of the ExPress Play reviewed that people with dementia enjoyed the experience (Riley et al., 2009). It also revealed that some participants accidentally selected the buttons while resting their hands on the bottom of the screen. This resulted in the decision to move the buttons to the upper part of the screen. Researchers also mentioned that confusion of the users was provoked by the promptings on the screen “start again”, “drag your finger around the screen to play music”, and “play music”. While the system was first intended for autonomous use, additional prompting by the researcher or carer was necessary for many participants to understand how to participate.

Recommendation 8
Positioning of buttons in electronic devices for AMT should be thought to prevent accidental selection (Riley et al., 2009).

Recommendation 9
If an electronic device is designed for autonomous use, prompting has to be simple but explicit enough to be understood (Riley et al., 2009).

Recommendation 10
When designing improvisation musical games for users without musical experience, it is important for the interface to guarantee playing of pleasing music; this can be done by using a single musical scale (Riley et al., 2009).

A second project that has also developed an electronic musical game for people with dementia is the MINWii (Boulay et al., 2011). It is a musical game based on a musical keyboard design, at is was specifically targeted to AD population. In this game, participants with AD point with a Wiimote Pistol on to a virtual keyboard displayed on a screen to improvise or play a song. A pilot study assessing the usability of this game in people with AD indicated that participants enjoyed the game. However, it also revealed that the users had trouble using the Wiimote Pistol and had a slow selection speed of the keys, hindering the lapse between notes and affecting the recognizability of the song. Because people with AD might struggle when organizing elaborate actions, it is thus important that the usage of technological devices require simpler operational actions.

Lancioni and colleagues (2015) assessed positive participation (such as singing, rhythmic movements, and smiles) of seniors with AD using simple operational actions to elicit song fragments. They found that using simple responses (such as clapping, waving or hand closing) to operate musical devices promoted engagement of people in all stages of the disease (Lancioni et al., 2015; Lancioni, O'Reilly, et al., 2013; Lancioni et al., 2019). Furthermore, they suggested that this self-regulated stimulation can enhance the level of reality awareness (Lancioni, Singh, et al., 2013) and mood of the users (Lancioni et al., 2019).

Recommendation 11
It is important that technological devices used for AMT require simple operational actions such as clapping or smiling (Lancioni et al., 2015; Lancioni, O'Reilly, et al., 2013; Lancioni et al., 2019).

Recommendation 12
Simple use electronic devices should be used when seeking to support the autonomous practice of AMT (Lancioni et al., 2015; Lancioni, O'Reilly, et al., 2013; Lancioni et al., 2019).

Recommendation 13
To enhance level of reality awareness, participants should have an active role (self-regulated stimulation) in musical creation (Lancioni et al., 2019).

In a different study (Lancioni et al., 2019), participants were provided with a tablet whose screen worked as a sensor. When touching it, it would present 10 s segments of preferred songs, and an absence of hand activation led the tablet to produce a prompt. The authors indicate that a simple and economic touchscreen technology such as the tablet they used can be a simple solution for people in all stages of AD to self-regulate music stimulation and to create positive engagement in the therapy.

Furthermore, the use of a tablet for a therapy-based program can allow to set up effective reminders (Lancioni et al., 2019) or stimulus to help the users with AD refocus their attention in case of a delayed or wrong response (Lancioni, O'Reilly, et al., 2013). This comes from the consideration that the use of reminders may be essential for seniors who have serious attention or memory impairments or when the therapeutic activity demands complex movements such as the use of instruments in a specific way. In cases where written instructions on technological devices are used, their design has to be adapted to the AD population by using large font size, clear font style, contrasting color (black text over white background), and simple and short sentences (Almor et al., 1999).

Recommendation 14

Electronic tablets are an economic and easily accessible option for participants to complement their therapy (Lancioni et al., 2019; Riley et al., 2009). Furthermore, they can be programmed to be used by each person according to their necessities (Lancioni et al., 2019).

Lancioni and colleagues (2019) also indicated that combined use of simple visual and verbal prompts could lead to a greater positive impact of a therapy. Other studies have also reinforced the finding that the use of multisensorial prompts throughout the intervention is a critical strategy to avoid participants from drifting their attention away and to promote their participation (Cevasco & Grant, 2003; Lancioni, O'Reilly, et al., 2013).

Recommendation 15

Continual multimodal (visual and verbal) prompting should occur along the session, especially when responses demanded are not intuitive or require higher cognitive demand (Cevasco & Grant, 2003; Lancioni, O'Reilly, et al., 2013).

Song Selection: Facilitator for Participant’s Motivation and Cognitive Stimulation

The correct music selection allows to benefit from the remaining emotional functions of seniors with AD and thus facilitate the stimulation of cognitive functioning (Bucks & Radford, 2004; Sakamoto et al., 2013). The preserved memory for music allows people with AD retrieve memories associated with music (Cuddy, Sikka, Silveira, Bai & Vanstone, 2017). For instance, the usage of music can help improve attention levels and evoke autobiographical memories as a result of the emotions associated with it (Cuddy et al., 2017; García et al., 2012; Simmons-Stern et al., 2010).

Music selection is also essential to increase the participant’s level of positive participation and to motivate him to respond (Lancioni, Singh et al., 2013). Song selection for the therapies must reflect on the individual’s musical preferences, experiences, and emotional associations; highly familiar and autobiographically important songs should be selected to emotionally involve participants in the activity (Cuddy et al., 2017; Lancioni, Singh et al., 2013).

Participants are often not able to communicate or remember the names of their preferred songs. Thus, a common strategy (Brotons & Pickett-Cooper, 1994; Lancioni et al., 2015; Lancioni et al., 2019) is to include the participant’s family members or other caregivers in the song selection and then present the participants with a brief preference screening of these songs. In addition to the indication of like or dislike from the participant, other strategies such as observing their alert or positive engagement behaviors in each song should be utilized (Brotons & Pickett-Cooper, 1994).

Recommendation 16

The song selection should be emotionally relevant for the participant (Lancioni, Singh, et al., 2013; Zhang et al., 2018).

Table 1 Recommended practices for Active Music Therapy design

Recommendation 1	To elicit positive participation and promote engagement, playing an instrument (by the senior with AD) to a musical

	piece should be chosen before other modalities of musical activity (such as improvisation) (Cevasco & Grant, 2003).
Recommendation 2	When implementing a verbal cue-oriented activity, choose instrumental music over vocal to avoid confusion between the verbal stimuli of the song and the vocal cues of the therapist (Cevasco & Grant, 2003).
Recommendation 3	Musical activities such as dancing, playing an instrument, and playing musical games are enjoyed by people with AD. To promote engagement in the therapy, a variety of these AMT activities that include minimum and simple instructions should be included (Brotons & Pickett-Cooper, 1994).
Recommendation 4	AMT activities should be flexible and able to adapt to each participants' needs (Brotons & Pickett-Cooper, 1994).
Recommendation 5	To synergistically impact all symptoms of AD, AMT activities should contain cognitive, motor, and musical tasks (Gómez Gallego & Gómez García, 2017; Ngandu et al., 2015).
Recommendation 6	Multimodal tasks that include pleasurable activities for the participant can be used to promote the engagement in activities (also included in the multimodal task) in which they would not voluntarily participate but that are helpful treating the disease (Cevasco & Grant, 2003).
Recommendation 7	The space retrieval technique can be used to teach people with AD new tasks (Benigas & Bourgeois, 2016; Creighton et al., 2015).

Recommendation 8	Positioning of buttons in electronic devices for AMT should be thought to prevent accidental selection (Riley et al., 2009).
Recommendation 9	If an electronic device is designed for autonomous use, prompting must be simple but explicit enough to be understood (Riley et al., 2009).
Recommendation 10	When designing improvisation musical games for users without musical experience, it is important for the interface to guarantee playing of pleasing music; this can be done by using a single musical scale (Riley et al., 2009).
Recommendation 11	It is important that technological devices used for AMT require simple operational actions such as clapping or smiling (Lancioni et al., 2015; Lancioni, O'Reilly, et al., 2013; Lancioni et al., 2019).
Recommendation 12	Simple use electronic devices should be used when seeking to support the autonomous practice of AMT (Lancioni et al., 2015; Lancioni, O'Reilly, et al., 2013; Lancioni et al., 2019).
Recommendation 13	To enhance level of reality awareness, participants should have an active role (self-regulated stimulation) in musical creation (Lancioni et al., 2019).
Recommendation 14	Electronic tablets are an economic and easily accessible option for participants to complement their therapy (Lancioni et al., 2019; Riley et al., 2009). Furthermore, they can be programmed to be used by each person according to their necessities (Lancioni et al., 2019).

Recommendation 15	Continual multimodal (visual and verbal) prompting should occur along the session, especially when responses demanded are not intuitive or require higher cognitive demand (Cevasco & Grant, 2003; Lancioni, O'Reilly, et al., 2013).
Recommendation 16	The song selection should be emotionally relevant for the participant (Lancioni, Singh, et al., 2013; Zhang et al., 2018).

1.9 Limits and Further Studies

To our knowledge, this work presents the first literature review to exclusively focus on documenting the effects of active music therapy on AD.

The findings of the effects of AMT over AD symptoms were consistent among the articles presented. To select the literature included in this literature review, potential documents were read and only included if their research protocol (if applicable), their criteria measures, and their results were explicit, clear to understand, and were consistent within the article. However, the quality of the studies was not vastly evaluated, and future studies should be done regarding the quality of the studies presented.

Unlike the many studies found on the effect of AMT over the symptoms of AD, limited work was available regarding the effect of AMT over the demented brain. Thus, the studies presented mostly consisted on research made on the beneficial effects that music listening and music playing have over brain structures and circuits that are known to be affected in AD. More studies focused on AMT over the AD brain should be conducted to allow for the consolidation of a theory of AMT action mechanisms over the AD brain.

In addition, we have not found any studies reporting improvement in functional autonomy regarding AMT. Thus, considering the literature's recommendations that to improve functional autonomy other modalities (such as motor and cognitive training) should be included in AMT, future studies involving multimodal AMT should be conducted to research possible improvements in this area.

Finally, this work concretizes the observed outcomes of several AMT experiments into a list of recommendations to aid researchers and practitioners to design and implement an active music therapy based on the characteristics of AD population. However, these recommendations should be taken as a general guide to design AMT interventions for AD population. Further tailoring should be done to the AMT's design depending on the circumstances surrounding the intervention (i.e., designing with a specific outcome in mind, to adapt it to the place where the intervention will take place, or to tailor it for population of people with AD that also have other impairments).

1.10 Conclusion

AD is a neurodegenerative disorder that causes decline in cognition, behavior, and functioning. The literature presented supports the use of AMT independently or as a complement to the regular therapy of people with AD.

AMT is a non-pharmacological approach that does not seek the sedative properties of other conventional therapies but engages seniors with AD in musical activities to help alleviate their symptoms. This article documented some of its reported beneficial effects in AD. For instance, engaging in AMT improves cognition and reduces anxiety and depression in mild and moderate AD, it reduces agitated behaviors in moderate to late AD, and it reduces delusions, hallucinations, and irritability at mild stages of the disease.

While AMT was found to improve cognitive, behavioral, and psychological symptoms, no beneficial effects were found over the functional autonomy of people with AD. Thus, multiple authors suggest that AMT further integrates motor and cognitive rehabilitation activities in order to achieve improvements in the functional sphere.

It is also noted that active music therapy requires multi-sensory, cognitive and motor tasks that down-regulate brain deterioration and potentiate the mechanisms of brain plasticity. Thus, it seems that music has a beneficial effect not only over many dementia symptoms but also over the demented brain.

The studies presented in the last section of this chapter helped to point out practical recommendations for a most efficient, autonomous, and engaging use of AMT in AD. The implementation of these recommendations (i.e., utilizing songs emotionally meaningful) on the design of AMT activities can not only positively impact AD symptoms, bus also help create a positive atmosphere where participants can regain a grasp on reality and indulge on an activity that brings joy to their lives.

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Chapitre 2. Co-design of a Musical Device to Autonomously Guide Seniors with Mild AD through Active Music Therapy Tasks

2.1 Résumé

La technologie peut permettre une utilisation autonome des thérapies non-pharmacologiques chez les personnes avec maladie d'Alzheimer. L'implication des utilisateurs dans le processus de création permet d'adapter les technologies à leurs besoins. Ainsi, à la suite des recommandations issue de la revue du chapitre 1, une méthodologie de co-conception a été utilisée pour créer un clavier musical pouvant guider de façon autonome les personnes au stade léger de la MA lors de séances de musicothérapie active (TMA). La méthodologie a consisté à développer un prototype du clavier pour TMA lors de séances individuelles avec des personnes avec MA (n=4) et des séances de groupes de discussion avec des proches aidants (n=4) et chercheurs (n=7). Le clavier musical résultant est surdimensionné, doté de sept touches, simple d'utilisation et adaptable aux préférences de couleur et musicales de chaque participant. Les dix tâches développées pour son utilisation comprennent des activités musicales, cognitives et motrices.

2.2 Abstract

Technology has proven to be a powerful tool for health professionals and patients alike. In the case of people with Alzheimer's Disease (AD), it can allow them to autonomously engage in non-pharmacological therapies. A successful practice to tailor new designs to the needs of the end users is to involve them in the creative process. Thus, following the recommendations presented in chapter 1, a co-design methodology was used to create a technological musical keyboard that can guide users with mild AD through active music therapy sessions. The process involved individual sessions with people with AD (n=4), focus group sessions with caregivers (n=4) and with researchers (n=7). The sessions allowed for the creation of a prototype for the musical keyboard that is oversized, has seven keys, simple to use

and that is adaptable to each participants color and music preferences. The ten tasks developed for its use include musical, cognitive, and motor activities.

2.3 Introduction

Alzheimer Disease (AD) is a growing world problematic that causes brain function decline, altering cognition, emotions, and functionality (Martin Prince et al., 2015). Many authors (Boulay, Benveniste, Boespflug, Jouvelot, & Rigaud, 2011; Imbeault, Bouchard, & Bouzouane, 2011; Kida et al., 2015; Lancioni et al., 2019) have suggested the use of electronic devices to improve the quality of life of people living with it. One suggested use of these devices is allowing seniors with AD to autonomously engage in activities or therapies to complement their other treatments (Kida et al., 2015; Lancioni et al., 2019).

In this sense, some commercial products exist such as Nintendo's Brain Age (2005) and Big Brain Academy (2005). Nonetheless, these creations have several limitations when used by people with AD. Among these, they require knowledge of technologies such as computers and video game consoles that many seniors lack (Imbeault et al., 2011; Nacke, Nacke, & Lindley, 2009).

Research is already being done towards creating such technology adapted to the needs of this population, but this field still has a great potential for development (Imbeault et al., 2011; Lancioni et al., 2019). For instance, Lancioni and colleagues (2019) created an electronic tablet that allows people with AD self-regulate their music stimulation, and, a music therapy game called MINWii that allows users with AD to engage in music therapy (MT) activities using a Nintendo Wiimote has also been developed (Boulay et al., 2011).

These two studies involve active music therapy (AMT), a non-pharmacological therapy (NPT) that is known to improve cognitive, behavioral, and neuropsychiatric symptoms in AD population (Gómez Gallego & Gómez García, 2017; Särkämö et al., 2014). Recommendations for further studies involving electronic devices to impart AMT have been encouraged (Kida et al., 2015; Lancioni et al., 2019). This is because due to the nature of AD, AMT requires guidance and supervision for the senior to engage in the sessions and complete them adequately (Cevasco & Grant, 2003; Cevasco, 2010). With the use of adapted technological devices, the elderly could engage in therapeutic sessions without having to rely on the schedule of their caregivers or therapists. This could represent an important relief for seniors with AD, their caregivers, and other family members.

To design solutions specially adapted for the needs and preferences of people with dementia, many authors have suggested the use of a co-design approach (Hwang et al., 2015; Niedderer et al., 2017; Rodgers, 2018; Tan & Szebeko, 2009). This approach seeks to integrate the end users into the design process (Asaro, 2000), allowing them to enable their voice and acknowledging their expertise of their own experience (Sanders & Stappers, 2008).

Therefore, and considering the benefits of AMT (Gómez Gallego & Gómez García, 2017; Särkämö et al., 2014), the main objective of this project is to co-design an electronic musical device and its related multimodal AMT tasks that can autonomously guide users with mild AD through AMT sessions, i.e. requiring minimal to no supervision from caregivers or therapists.

A keyboard (similar to a piano) was chosen as the base instrument for this therapy for four reasons. First, it has been reported as attractive and engaging by older users (Benveniste et al., 2013). Second, cognitive gains from piano lessons are easily transferred to daily tasks. For instance, training with piano improves cognitive abilities associated with executive function, perceptual speed, and visual scanning which are often impaired in AD (Bugos, Perlstein, McCrae, Brophy, & Bedenbaugh, 2007; Seinfeld, Figueroa, Ortiz-Gil, & Sanchez-Vives, 2013).

The third reason for choosing a keyboard is that procedural memories (such as learning to play a short melody on the piano) are preserved in AD (Van Halteren-Van Tilborg, Scherder, & Hulstijn, 2007). This means that seniors with AD are expected to improve their performance over time. Lastly, the keyboard (similar to a piano) has an intuitive design, eliciting a relationship between the position of the keys and the increasing frequency of their tones.

2.4 Methodology

A co-design approach (Morales, Rousseau and Passini, 2012) was set up to reach the objective. It involved three methodological phases: 1) development of a starting point for the electronic device and the therapeutic tasks, 2) individual co-design sessions with people with mild AD, and 3) validation of the designs through focus group sessions with caregivers and with researchers. Each phase generated a proposal for the electronic device and/or for the therapeutic tasks which were used as departure points for the following phase. Written notes and audio recordings were collected from each design session.

Participants

Recruitment of seniors with mild AD (n=4) for phase 2, was done by reference of patients diagnosed with AD by the Interdisciplinary Memory Clinique of Quebec City. Criteria for their inclusion was having between 60 and 85 years old, having a diagnosis of AD, having obtained a score between 22 and 28 (mild AD) in the "Mini-Mental State Examination" (Folstein, Folstein & McHugh, 1975) test during the past 6 months, and being naive to playing a musical instrument. Having any motor or cognitive impairments caused by a condition other than the AD was an exclusion criterion. These selection criteria sought to facilitate the interactions and the participation of our target population in the design sessions. Caregivers (n=4) and researchers (n=7) were identified by the project coordinators to participate in phase 3. The tables with the characteristics of all participants in this study is found in annex A.

To ensure ethical conduct, the study was submitted to and approved by the research ethics committee of the Institut de réadaptation en déficience physique de Québec (IRDPQ). Written consent was obtained from participants prior to their participation (certificate number EMP-2017-541).

Phase 1: Development of a Starting Point for the Musical Electronic Device and the Therapy.

Aiming to create the starting point (Morales et al., 2012), five meetings were held by the interdisciplinary research team over a one-year period, to determine the global requirements of the electronic device and of the therapeutic tasks. During these reunions, multimodal tasks that could be included in the therapeutic session were discussed. Through brainstorming, the research team came up with ideas on how to integrate the desired activities into a therapy for the goal population. These proposals were merged into the therapeutic tasks proposal number 1 (TT1).

Simultaneously, the first conception of the electronic device was developed and named musical keyboard 1 (MK1). To create it, the following points were discussed until consent was established and until the team decided that designing with the users was needed to further the design solutions: a) technological resources and limitations, b) hardware of the therapeutic device (shape, size, material, color, input methods such as on and off buttons, volume, musical buttons, and buttons' lighting), and c) software and user experience of the device (adequate assistive prompting, effective multisensory cues to maximize performance, the use of multimodal feedback, and, an adequate in-game challenges such as dynamic difficulty adjustment to match the user's skills).

Phase 2: Individual Co-design Sessions with People with AD.

This phase consisted of two individual sessions with each participant with AD.

The first session began with the presentation of the project followed by a semi-structured interview aiming to get to know the participants' sociodemographic background and to explore their interests, hobbies, and their day-to-day life. They were also asked if they had participated in NPT to improve their symptoms related to the disease or their quality of life. This first part of the session lasted an hour, in which the participant was encouraged to feel free to talk about his life and was encouraged to express what he enjoyed doing during an average day.

This first section allowed to establish rapport and make the participant feel more comfortable speaking with the interviewer. It also allowed the interviewer to explore the participants' daily experiences and thus, establish possible design ideas for the device and therapeutic tasks that each participant would be interested in. It also allowed to superficially grasp the state of their cognitive functions, so co-design techniques could be adapted to each participants' abilities and skills, and to better develop the design session (Hendriks, Slegers, & Duysburgh, 2015).

Then, the project and its objectives were briefly presented again to the participants to ensure that they remembered the objective of the session. The envisioned concept of the musical device and the therapy previously developed by the research team was then explained. Participants were encouraged to decide the material, the color and the shape they would like for the device.

To decrease the cognitive load and promote participation, co-design techniques were adapted to work with each senior at the spot (Dawe, 2007; Hendriks et al., 2015; Lindsay et al., 2012). Paper prototypes were used to illustrate which features of the electronic device they could modify (such as shape, color, and size) to facilitate their imagination and communication of their thoughts (Jury, 2016). In addition, presenting the participants with choices of LED lights and different materials, such as flexible plastics, gelatin, cotton, and fabric, allowed them to personalize the prototype device and grasp an idea of what the final result would feel and look like.

TT1 was also discussed with the participants. The melodies considered for TT1 were played to the seniors and they were asked if they recognized them. Also, to clearly exemplify the tasks for TT1, they were presented with the game of Simon (1978); this game was installed in an electronic tablet and has a similar game mechanics than TT1. The participants were instructed on how to play and were invited to try the game. After examining TT1, they were encouraged to ideate different tasks to include and to describe or demonstrate them over a paper prototype of the device.

Given the information obtained from the first session with each participant, a second task proposal (TT2) and a second musical device proposal (MK2) were developed. Also, a test interface containing a trial for each of the tasks of TT2 was then created.

The second session started with a short reminder of the project and what was done in the past reunion. This presentation was followed by inviting the participants to use the test interface with TT2. This interface consisted in an app presented in a Samsung electronic tablet. The app guided the users through the song selection and trough each of the tasks developed in session 1. It had written instructions for all the tasks created in session 1 and it included a video tutorial for the spaced retrieval task (see task number 7 in annex B) that is similar to Simon (1978).

After participants accomplished each task, the following features of the user experience were discussed with them for improvements: clarity, relevance, and modality (visual, text, audio) of the instructions, and attractiveness and difficulty of each task. These modifications gave place to the creation of TT3. Also, during this session participants chose the melodies they wanted their therapy to include. Foreseeing possible difficulties that participants could have when remembering songs to include in the therapy, a tablet was used to search with them popular songs of the music genres that they preferred. Their reaction when listening to the music melodies was observed, and along with their verbal opinions, the songs to include for the tasks were decided (Brotons & Pickett-Cooper, 1994).

Phase 3: Validation Sessions with Caregivers and Researchers

In order to validate the TT3 a focus group session was held in, where four caregivers of people with AD evaluated the results obtained in the previous step and determined their pertinence. The caregivers were two elderly people who were married to a person with AD, a young adult who had cared for his grandmother with AD and a middle-aged adult who was caring for her father with AD. Two of the caregivers were from the Canadian Quebec province, the third caregiver was from Mexico and the fourth caregiver was from Iran. All currently resided in Quebec.

The focus group session started with a brief explanation of the project and was followed by the Musical Keyboard proposal number 2, and the TT3 proposal. Subsequently, participants were given time to inquire about the project. Then, the characteristics of these proposals were presented and suggestions for improvements were discussed until a consensus was achieved. Some of the details that were discussed included size, material, color, and security of use of the electronic device, the pertinence and order of the tasks, clarity, relevance, and modality (visual, text, audio) of the instructions for each task, and the duration of the session. From this session, TT4 proposal resulted.

Another focus session, now with seven researchers from the Laval University in Quebec, Canada was held. To allow the triangulation of different perspectives and expertise, the research domains of the researchers were different from each other, but they were all pertinent to the project (their respective research domains can be found in annex A, table 4). The procedure of the meeting was the same as with the caregivers, with the "improved version" where all the comments of the session with the caregivers were incorporated. Through discussion, the comments for improvements reached a consensus originating MK3 and TT5. The prototypes' design was thus modified accordingly.

Data Analysis

Detailed notes were produced to capture the highlights from the semi-structured interviews and each group's discussions, including observations of the feedback and reactions to the images, videos, sounds, textures, models and games presented to the participants. These notes were independently contrasted with the raw audio recordings of each session by the main author and a second researcher (J Nino) to ensure that no important details were omitted. A thematic analysis was conducted to identify recurring patterns and design requirements in the detailed notes after each session. The themes that emerged were presented to the participants of the next session to feed the discussion and collect their opinions and evaluations on the matter. The themes resulted in critical design considerations that were integrated into the final design of the device and its tasks.

2.5 Results

The Musical Electronic Device and the Therapy (Starting Point)

Following the recommendations made in a literature review on AMT in AD (see table 1 in chapter 1), the research team agreed that the therapeutic tasks on TT1 (presented later in this section) should integrate active music therapy, space retrieval, and physical activity components. Then, the concept of a therapeutic musical keyboard that would guide participants autonomously through a multicomponent active MT arose.

Figure 1 is the musical keyboard option 1 (MK1) (see Figure 1). It had oversize proportions which required arms and body displacement to produce a melody. MK1 would be positioned horizontally on the wall at the height of the user's face to promote postural control by requiring participants to hold an adequate posture during therapy sessions. Figure 2 illustrates the partial squatting position for participants to adopt while performing the AMT tasks. As a safety measure, the keyboard would constantly remind the participants to adopt a partial (standing) squatting position (see Figure 2).

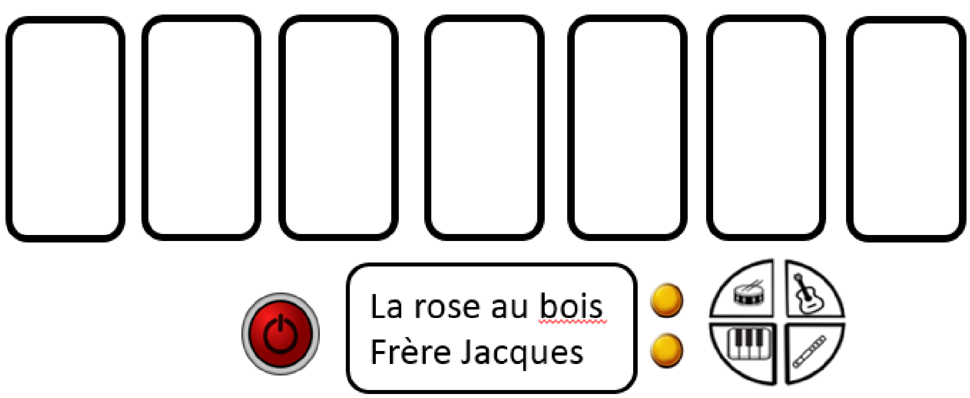

Figure 1 Musical keyboard 1: option 1

Figure 2 Partial squatting position for participants to adopt while performing the AMT tasks

To further promote the displacement of the trunk and upper limbs during therapy, the possibility that the seven musical keys of the keyboard would be arranged in an inverted U shape (see Figure) was left for discussion with the participants with AD. This shape would force users to lean their trunk to reach the lower keys and raise their arms to touch the upper keys, exercising postural control and stretching.

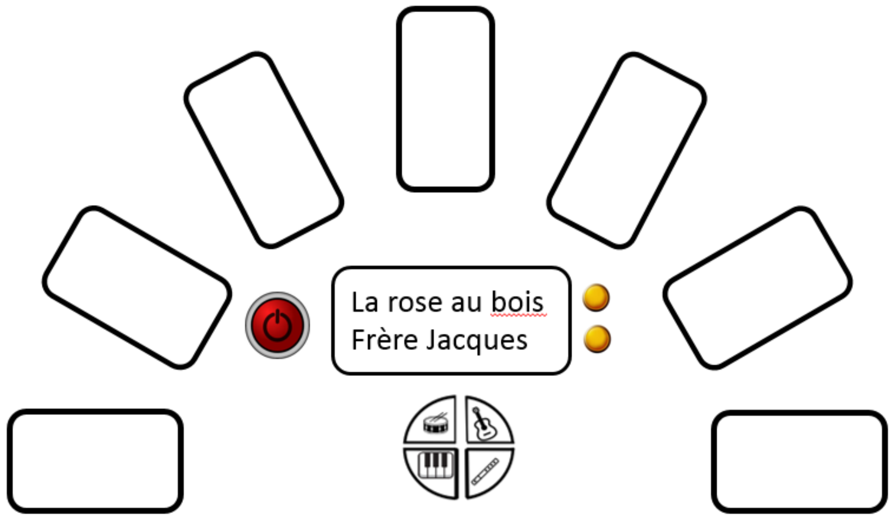

Figure 3 Musical keyboard 1: option 2

Due to the decreased visual ability in seniors, high contrast between adjacent keys was decided to be mandatory. Furthermore, to direct the attention of the user towards the keys that must be played, the group decided that each key should light up and emit sound. These multisensory cues relate the location of the keys to their sound, exercising the user's visuospatial memory.

An LCD display at the center of the keyboard would present instructions for the participants (i.e., listening, remembering, reproducing). The instruction design was adapted to the AD population by using large font size, clear font style, contrasting color (black text over white background), and simple and short sentences.

To allow the users to choose the song that they prefer to practice in that session, two buttons were placed to the right of the LCD display. A big red button with a power symbol placed to the left of the LCD screen could allow turning the device on and off.

Regarding the tasks, the difficulty would dynamically adapt to the user's skills and praise the user's efforts, without recriminating their errors, in order to avoid frustration. Furthermore, if the user is unable to perform the task adequately or is making several mistakes, the device should automatically restart the task, decrease the difficulty and replay the instructions. These instructions should always be available to the users in case they forget them.

During the session, the need to promote free use and creativity was repeatedly highlighted as the use of only predefined tasks might limit the freedom in playing music. This was addressed by giving the user the option to choose which song they want to play and the timbre of the instrument (piano, flute, guitar or drums).

The multimodal task (TT1) that resulted from this phase consisted of listening, memorizing and playing melodies through a spaced retrieval technique (see task 7 from annex B). It was thought to particularly target cognitive-motor planning and working memory. The options for melodies chosen for the session were part of songs that are usually taught during infancy in Quebec.

Before the task begins, the keyboard device would play the short melody once. Then, the keys corresponding to the first two notes will sequentially light up. The user would then be required to reproduce the segment of the melody by hand-pressing the keys in the same order as they lit up. Once the order is reproduced, another key (note) would be added to the sequence and so on. Hence, over practice, the series would become progressively longer until the whole melody is reproduced. In case no key was pressed after a time limit, or if any errors were detected, the keyboard would reproduce the sequence again.

Perspectives of People with AD from the Co-design Sessions regarding the MK1 and TT1

There were two females and two male participants in the first session of this phase. However, one of the female participants was unable to participate in the second session of this phase due to requiring hospitalization from injuries not related to the project. All participants were under pharmacological treatment, but none had participated in non-pharmacological treatments. Two participants (one male, one female) lived with their spouses and the others lived alone. Two were retired, and the other two lived from economic or governmental aid. All participants but one (participant 3) were born and had lived in the Quebec province in Canada for most of their lives. Participant 3 was born in England but had lived in Quebec for more than two thirds of his life.

During all sessions, the reactions of the participants (smiling, nodding, excitement, anxiety) were carefully observed to complement their verbal responses and to decide when to shift the attention towards relaxing subjects that were not cognitively demanding.

Participant 1 had the greatest difficulty to understand the project and often shifted his attention towards subjects external to the project. The session was not as challenging for the other three participants. Through eventual reminding of the concept of the AMT keyboard, they could retain the concepts in mind long enough to complete the co-design activities. Contextual support was often given to support their language struggles. Researchers and participants used paper models to explain and to understand how the tasks would take place.

With guidance and support, participants could ideate the seven tasks (see tasks 1,2,3,6,8,9 in annex B) that were included in TP2. The first three tasks aim to familiarize the user with the keyboard, warm up and stretch. The remaining tasks target attention, auditory discrimination, work memory and recognition memory. Due to the interactivity requirements of the new tasks, it was decided to use a tablet with a touch screen instead of an LCD display.

Furthermore, the interaction of participants with the paper keyboard prototype made evident the need to resize it. The size of the keyboard was decreased because the original size left some keys outside the field of view and encouraged lower limb displacement, which could be potentially unsafe for some users.

When designing MK2, all participants preferred the inverted u shape for the keys' positioning. They preferred that most keys had different colors because they said it was a visual aid to remind them that each key had a different note, but the patterns in the colors and the shades and luminosity selected by each participant were different (see Figure). The choice in key shape was different between all participants.

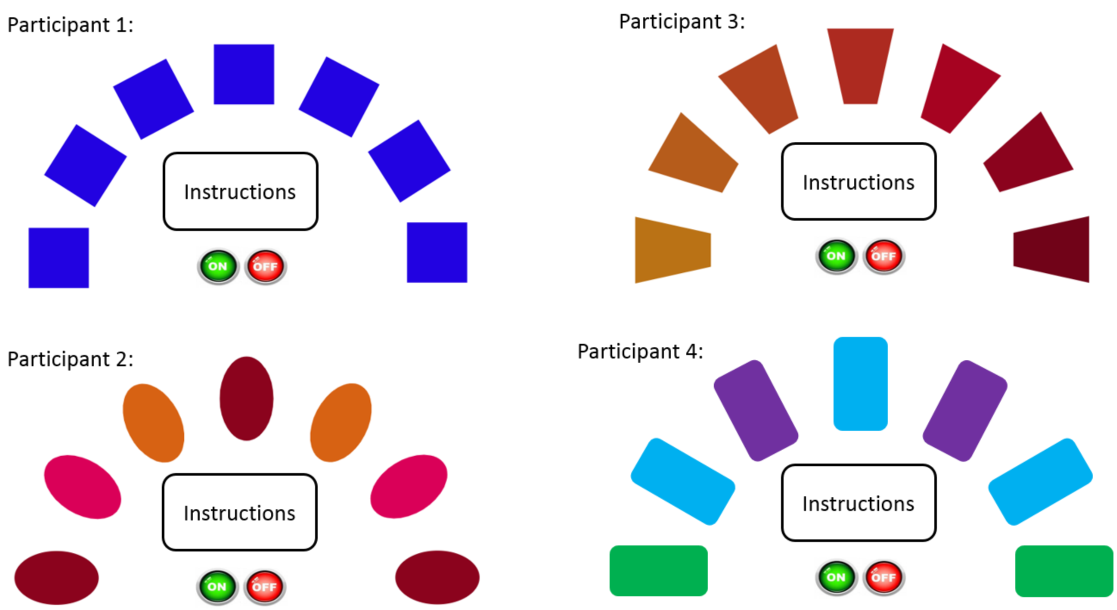

Figure 4 Musical keyboard 2: designs of each participant

Regarding the material for the keys, participant 1 and 2 selected an opaque but still transparent plastic and participants 3 and 4 selected transparent plastic with gel balls inside that refracted the light when the key lit up.

Participants were uninterested in changing the timbre of the keyboard, so this feature and the corresponding buttons were discarded. Also, all participants found separated ON (green) and OFF (red) buttons to be more intuitive than a single ON/OFF button. In this regard, buttons with text labels instead of symbols were preferred by the users.

During session 1, when participants were invited to play the game “Simon” in the tablet (a game with a similar game mechanics than our spaced retrieval task), the need for a tutorial video that accompanied the verbal and written instructions for the spaced retrieval task became evident.

All participants except participant 1 (who only recognized three out of five songs) recognized all the traditional songs included in the musical tasks. When the melodies were played, they would start humming or singing along and would have a happy expression. Despite this, they preferred to include in the therapy other songs that they liked best. While selecting these songs, the variety in selection was evident, including classical, rock and folk music. All participants except number 1, mentioned several times that they liked the project and they seemed to enjoy the co-design process.

Consensus for the Final Musical Keyboard According to Caregivers and Researchers

Discussion from the two focus group sessions had several improvements in common. In both, the length of the session was thought to be too long for many seniors with AD. Also, both groups considered that it was important to have the possibility to add more songs for users not to get bored after long-term use.

The need to make instructions more concise arose in both groups. Instructions were improved over the discussion with the caregivers' focus group, and thanks to the help of one participant from the researchers' group (FG2) several days after the focus group. In both groups, it was agreed that the written instructions should remain on the screen throughout each task. In addition, FG2 decided that each task should include a video tutorial besides the written instructions.

The initial need for greater freedom and expression mentioned in phase 1 arose in FG2. Thus, a task addressing this necessity was created (see task 10 in annex B). In the task, a melody will be played in the background with a different timbre from the keyboard and the user will be invited to touch any keys to play along with the song. During the task, the pitch of the keys will be adjusted to fit the scale of the background melody, so any sequence of keys makes musical sense. However, it was agreed that not all participants would feel motivated to participate in this activity, so the device would profile each participant during the first two AMT sessions. The device could thus evaluate the number of responses the user makes during the first two sessions in the task and could ask them at the end of the task if they enjoyed it. Then, it could adapt the time it would last and even eliminate it in case participants do not enjoy it.

Regarding MK3, FG2 agreed that each key in the device should have a different color to avoid confusion. The user will be able to select between four preset color configurations. It was agreed that each key should have a different texture to stimulate tactile memory and further allow for a multisensorial association. Regarding the shape for the keys, it was stated that they should have a shape in between those chosen by participants in phase 2.

The resulting keyboard (see Figure) is placed horizontally on the wall at a height such that the tablet is in front of the eyes of the user. It is 110 cm long, has a height of 90 cm and is 3 cm thick. It has seven musical keys made of silicon, each with a different texture, and each emits a different note when activated. The keys are organized in an inverted U shape and the senior can choose their color among four options (see Figure) at the beginning of each session. Under the middle key, there is an electronic tablet and below it, there are two buttons, one green (ON) and one red (OFF). All the components are mounted on an opaque plastic film that covers the wiring connecting them.

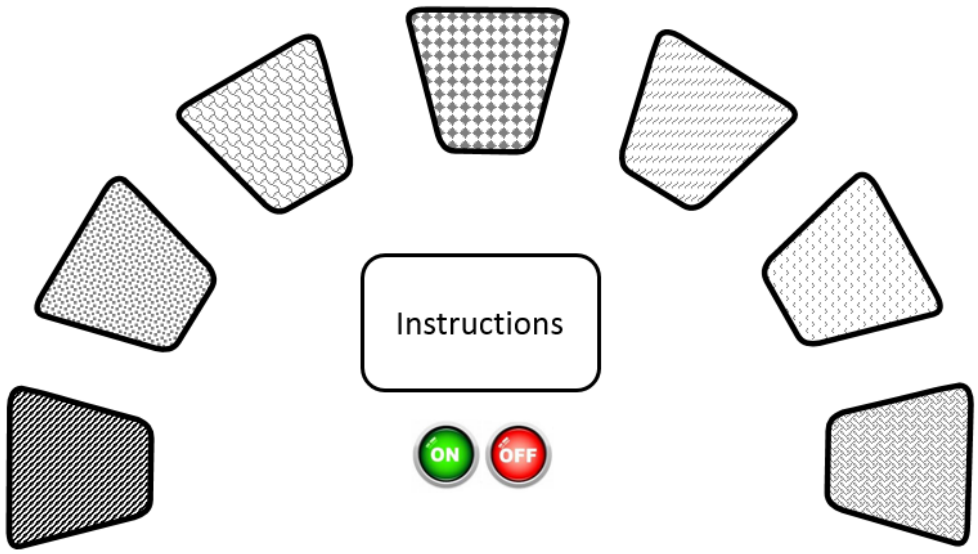

Figure 5 Musical keyboard 3

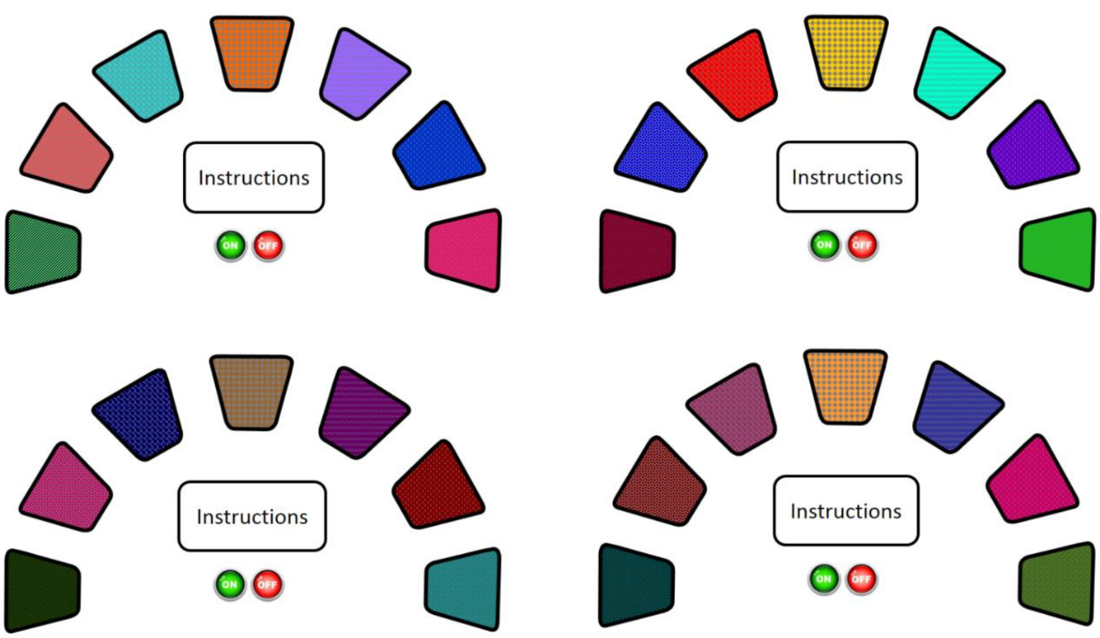

Figure 6 Musical keyboard 3: color options

Final Musical Keyboard Device

The musical device will come with pre-established widely known melodies and it will also allow to easily add other new melodies manually. During the first session, the device will ask the user if he recognizes the pre-established melodies and whether he likes them or not. Also, during the first two sessions, the keyboard will profile the user to adapt the amount of time the user will spend in the improvisation task.

Once the keyboard is installed and the power plug connected, the tablet boots directly to the full-screen application, and automatically communicates with the keyboard controller (shown as CTRL in Figure).

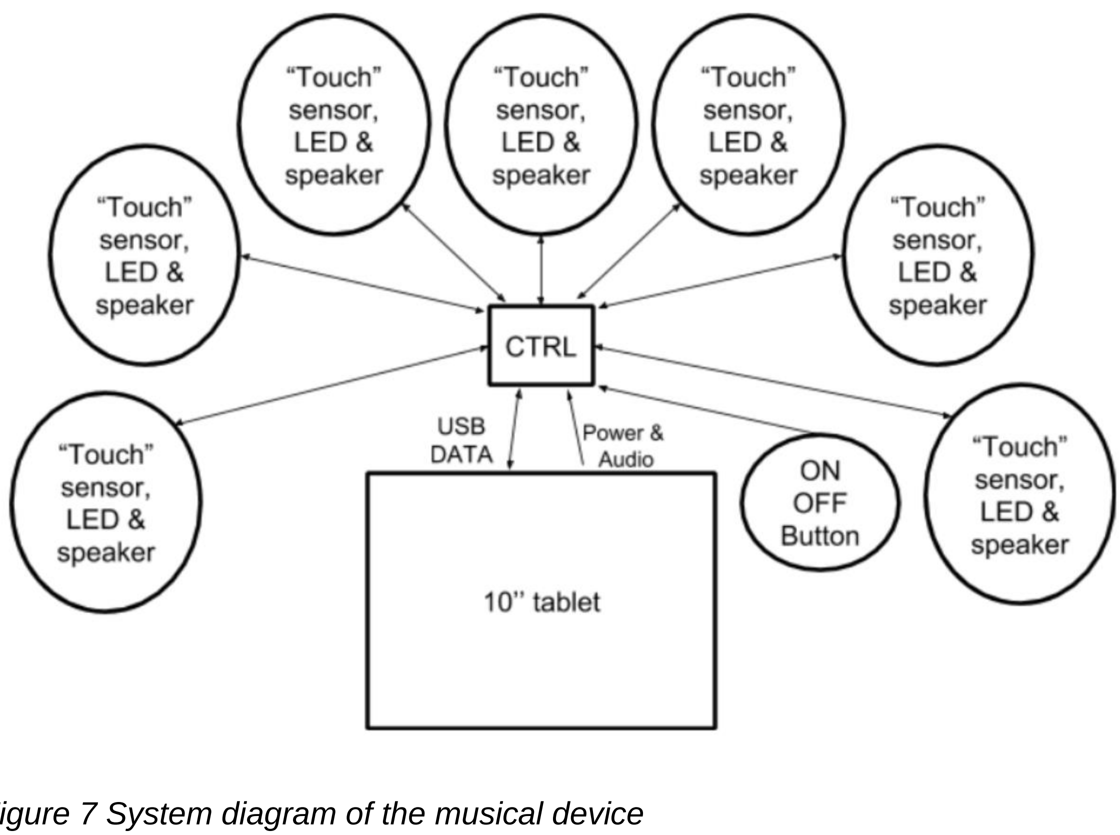

Figure 7 System diagram of the musical device

The keyboard controller is connected to the tablet through USB and audio ports and is directly connected to the seven “key modules” and the ON/OFF buttons. Each key module contains a capacitive touch sensor, an RGB LED (multicolored that allow changing the color of the keys), and a speaker in a textured silicone casing. The controller receives commands from the application to configure the color of each LED and to control the activation of each LED and speaker. It also reports the status of each key and the ON/OFF buttons to the application.

The application works as a finite state machine with only three possible states, Idle, Welcome, and Tasks (see Figure). The Idle state has a low power consumption while waiting for the user’s input between therapeutic sessions. The Welcome state is designed to salute the senior, to show a brief video presenting the keyboard i.e., that each key emits a different sound and that touching them activates the sound, and to allow the selection of the keys’ colors. Finally, the last state manages the tasks and provides clear instructions to guide the seniors through them.

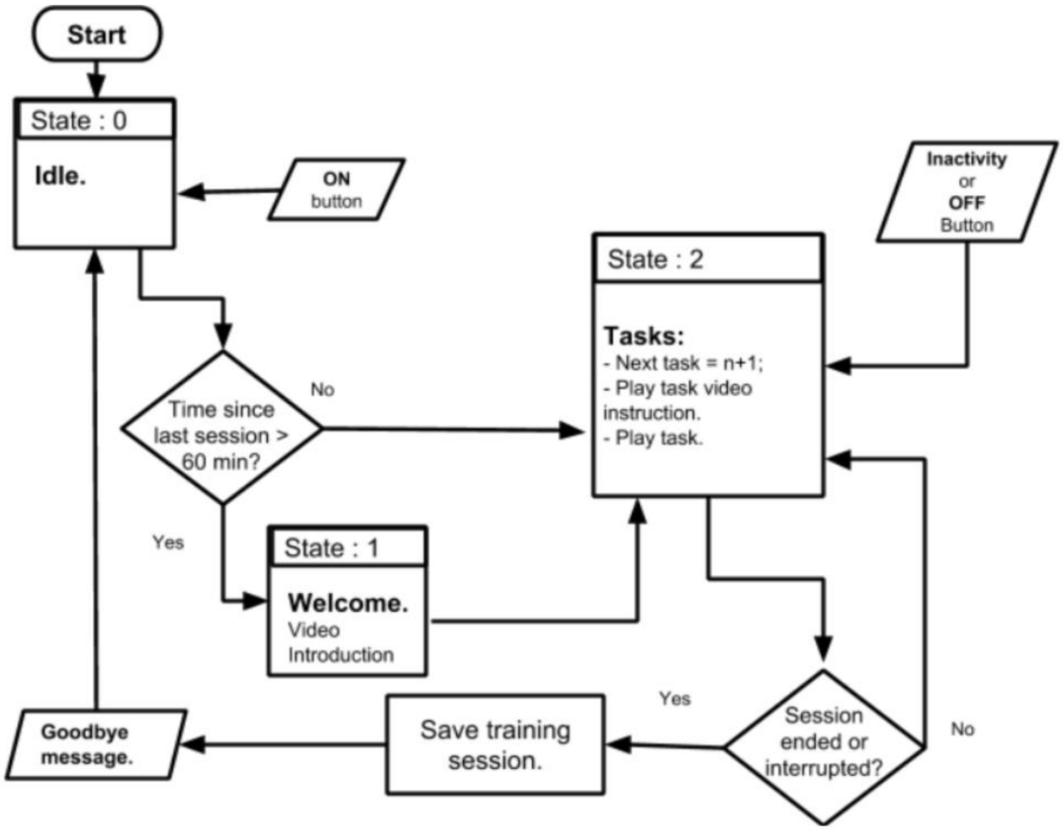

Figure 8 Execution flow chart of the application

Upon launch, the application goes into “Idle” state, where the key modules are disabled, and a dark gray screen is displayed. The program indefinitely waits for the user to press the ON button to change to the next state, “Welcome.” After the Welcome state is over, the system will automatically proceed to the Tasks (details of the tasks and their presentation order is presented in the table attached in annex B).

At the beginning of each task, there is a short video indicating to adopt a partial (standing) squatting position (see Figure). Then, a short video of a person interacting with the keyboard with concise oral instructions is displayed for each task. This video can be reproduced again by the user whenever needed by touching the “replay instructions” button on the screen. Meanwhile, the concise instructions remain written on top of the screen throughout the task.

After the completion of any task, the system will display a completion message, it will save the progress and return to the Idle state if enough tasks have been completed for the day (see next paragraph); else, it will proceed to the next task.

To avoid physical fatigue, the keyboard will ask the person to indicate their energy level from 0 (without energy) to 5 (full of energy) after the first 10, 15, 20, 30 and 45 minutes of the session. Depending on the answer, the keyboard will adapt the duration of the rest of the session. Over time, the physical performance of the senior is expected to improve, so when he is capable of completing three consecutive sessions of 45 minutes without feeling tired, the inquiries from the keyboard will only take place after 30 and 45 minutes.

During the Tasks state, the system is actively polling for interruptions caused by a period of inactivity (5 min since the last key touched) or by pressing the OFF button, which will cause the session to be paused, marked as incomplete for the rest of the day. The progress will be saved into the file system and the system will change to the Idle state.

If the session was left incomplete during the previous hour and the ON button is pressed, the keyboard will automatically return to the beginning of the task left unfinished. If more than one hour has passed, the session will start from the Welcome stage.

The application will automatically log events into a CSV file in an external SD card. Such events are the start and end of each session and tasks, the responses for each task (reaction time, correct/incorrect key activation by the user, the maximum number of consecutive correct/incorrect responses for each task), and the interruption of a task (inactivity/OFF button).

2.6 Discussion

The main objective of this project was achieved. We were able to co-design an easy to use electronic musical device designed to autonomously guide users with mild AD through AMT sessions, and ten AMT tasks.

During the research process we noted that despite research recommending the use of NPT to treat AD (Olazarán et al., 2004; Olazarán et al., 2010), none of the participants in this study, said to be involved in NPT. This was due to reasons such as lack of information, lack of access to these types of therapies, and lack of economic resources, and the belief that only pharmacological therapy could benefit them. This finding further highlighted the relevance of our project.

The following discussion will address 1) the instructions and multimodal promptings, 2) compensating for cognitive difficulties, 3) customizability, 4) research limitations and future directions.

Instructions and Multimodal Promptings

Just as evidence has indicated, the need to make instructions concise and specific (Almor et al., 1999; Bayles, 2003), and to support oral instructions with written ones that remain throughout the task (Boulay et al., 2011) was evident in all phases. Furthermore, we found that the use of video prompting was more easily comprehensible than just oral and written instructions. Consistent with previous studies, people with AD tended to drift their attention easily, thus, the need for the keyboard to have minimal distractions (Hopper, Bayles, & Tomoeda, 1998) and to attract their attention to important things with multi-sensorial stimulation was imperative.

Compensating Cognitive Difficulties

The interaction with the prototypes and allowing participants with AD to use and test different materials and colors for the device allowed them to generate their own ideas and enable their voice, overcoming their cognitive limitations. This is particularly relevant in this population because it is common for people who are more cognitively able, to talk over the seniors with AD and to make decisions for them (Jury, 2016).

Accordingly, most of the creative process was held during the second phase of the project. Thus, while most caregivers and researchers concentrated their efforts towards the functionality and to adapt it to attend and compensate the cognitive impairments of the users, the end users were the ones most interested in making the design into something they enjoyed.

Customizability

It is known that standardized designs that can adapt to each user (i.e., customizable), have better health care outcomes (Chalfont, Milligan, & Simpson, 2018). This was again shown to be important, e.g., while some participants said that warm colors made them feel calm, others said it made them feel sleepy and down. This was even clearer in music selection; all participants chose different genres of music, and from different eras. They all stated they preferred their selection over other popular known songs. Accordingly, evidence shows that music selection in music therapy should have a sentimental value for participants, which is important to facilitate learning (Särkämö, Altenmüller, Rodríguez-Fornells, & Peretz, 2016).

Research Strengths and Limitations

To enhance the trustworthiness of this study, many strategies were followed (Krefting, 1991).

First, methods of data recollection were discussed and decided by two members of the research team during the entirety of the project. Also, the implementation of the techniques by the interviewer were supervised and instructed by a co-design expert during two interviews with AD participants and during the focus group session with the caregivers.

It was important that participants with AD felt comfortable with the interviewer. People with dementia can sometimes be suspicious of others and might not want to open up or participate. The rapport section was thus longer that what is usually expected in other situations. This allowed participants to become accustomed to speaking openly with the interviewer and it facilitated them to openly comment on the project. The reviewer had had four years of previous experience interviewing people from different backgrounds and with different living situations which allowed her to adapt to each participant.

Because people with AD usually present difficulties explaining their thoughts many other techniques that were used to allow them express themselves helped also to enhance the truth value, Observing the performance of participants during the application of different techniques i.e., while using the paper prototypes and while playing the game “Simon”, allowed to triangulate the data methods and complement what participants communicated orally. These mentioned techniques aimed to identify patterns in interests and in situations that people with AD might encounter while interacting with the prototype.

A technique that the interviewer used during most part of all the sessions was to reformulate what participants said. This was done in order to ensure comprehension from both ways. This because all sessions took place in the French language, which is not the mother tongue of the interviewer. In this sense, the interviewers’ language barriers were also diminished with supporting physical material and by the enactment from the interviewer of how to interact with the keyboard. Reformulation was also made when previous knowledge seemed different from a given answer from any participant with AD; questions from the interviewer were reformulated in the moment or further during the session.

The several individual sessions, the focus groups with caregivers and the focus groups with researchers from different domains allowed to further triangulate the data and to observe the problematic from different perspectives. Also, because all the sessions were recorded, and notes were taken during the sessions, direct quotes were available for critical assessment all throughout the project.

Recruitment of participants for phase 2 was more difficult and took longer than we had anticipated. Initially we were expecting to have eight participants in this phase instead of four. Despite this, the fact that their level of education, and that their socio-economic status varied strongly, contributes to enhance the applicability of our study. Also, one of them was born and had lived a great part of his life in a different continent. Moreover, among the caregivers who participated, two had recently moved to Canada, and their experience caring for their relatives with AD had been in their home country. This and the participation of researchers from different domains allowed to co-design a prototype that is targeted not only for people from Quebec but that could be easily used by or adapted to other populations.

Future Research

Studies assessing the usability of the musical device created should be done to further improve it. Also, a pilot study could then assess the effects of using the device over outcomes such as working memory, attention, mood, self-esteem, and Behavioral and Psychological Symptoms of Dementia, e.g., agitation, depression, and anxiety. This could allow understanding of the effects' scope.

While this project was addressed to people with mild AD, further studies could explore and adapt the keyboard for its use in people with moderate and advanced AD. Furthermore, because the use of AMT has proven to be effective to improve symptoms from other dementias such as motor, affective, and behavioral functions in Parkinson's Disease (Pacchetti et al., 2000), the existing tasks could be adapted or new tasks could be created to address other neurodegenerative diseases affecting the cognitive and motor function.

2.7 Conclusion

The study utilized a co-design approach with different phases and sessions to customize a musical device adapted to the needs and preferences of people with mild AD. In general, participants in all phases of the project enjoyed the co-design process. However, the end users were particularly active and creative when participating in the sessions.

Seniors with AD might experience difficulties expressing their thoughts or understanding complex ideas. But, as with any other population, adapting the techniques to their characteristics and utilizing physical material and visual aids, can allow them to better understand and communicate. This can help create confidence in them and will promote their engagement in the activities.

Because working with people with dementia requires adaptation of different techniques, it is also relevant to mention that cherishing and working with the characteristics of each individual is critical to promote their participation in the co-design sessions. Overall, the work and its achievements showed that collaborating with the end users provide important insights and design solutions that might otherwise have been overlooked.

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Résumé du Chapitre 2

Le chapitre 2 a présenté le processus de co-création qui a abouti à un clavier musical adapté aux besoins et aux intérêts des personnes au stade léger de MA. Dix tâches ont également été obtenues à partir de ce processus et elles composent la session de TMA par laquelle l'appareil musical guidera ses utilisateurs. L'ensemble du processus a été supporté par les résultats obtenus au chapitre 1.

La discussion générale qui suit intègre les concepts et les résultats des deux chapitres pour proposer de futures directions et dépasser les limitations de l'étude.

Discussion

Le but de la recherche était de proposer un dispositif musical électronique permettant aux personnes au stage léger de la MA de s'engager de manière autonome dans des sessions de TMA. Cet objectif a été atteint en écrivant d'abord une recension des écrits (objectifs spécifiques 1,2,3,4) concernant les effets bénéfiques de la TMA chez les personnes avec la MA et qu'incluait une description des conditions et des approches pour favoriser et susciter leur participation autonome dans les sessions de TMA. La recension des écrits a guidé la prochaine étape pour atteindre l'objectif spécifique 5 de conception et de validation d'un prototype de clavier musical pour la clientèle avec MA. L'utilisation d'une approche de co-conception a permis en fait de concevoir le dispositif musical avec succès et de l'adapter aux besoins de la population ciblée afin qu'elle puisse participer de manière autonome à la TMA.

3.1 Musique, Cerveau et Mémoire Musicale en MA

La recension des écrits nous a permis de présenter l'effet positif de la TMA sur l'état cognitif général et les symptômes neuropsychiatriques de la MA. Cet effet a été expliqué en raison du rôle important qui joue la musique dans notre vie en régulant les émotions, les interactions sociales et la communication (Lipe, 2002; Turino 2008). Dans ce sens, la simple écoute de la musique engage bilatéralement les structures cérébrales associées à la perception acoustique (Alluri, Toiviainen, Jääskeläinen, Glerean, Sams & Brattico, 2012), à la mémoire de travail, à l'attention (Janata, Tillmann & Bharucha, 2002), à la mémoire épisodique, à la mémoire sémantique (Janata, 2009), à la réponse émotionnelle (Koelsch, 2010), et à la perception et la compréhension du rythme (Zatorre, Chen & Penhune, 2007). En outre, créer ou jouer de la musique implique d'autres réseaux cérébraux impliqués dans la coordination visuomotrice, les mouvements volontaires, l'apprentissage procédural, la cognition et les émotions (Yinger et Gooding, 2014; Alluri, 2012).

Notamment, la TMA est si importante pour la MA parce que les structures cérébrales qui traduisent la mémoire musicale (aires cingulaires antérieures et motrices) ne sont pas beaucoup touchées en la MA (Jacobsen, Stelzer, Fritz, Chételat, La Joie & Turner, 2015). Cela signifie que la perception et la reconnaissance de la musique familière, ainsi que les émotions qui l'accompagnent, sont épargnées même aux stades avancés de la maladie (Matrone & Brattico, 2015).

Étant donné que la mémoire musicale est épargnée, il a été recommandé de développer des stratégies thérapeutiques qui en tirent parti pour améliorer la qualité de la vie des personnes avec MA (Matrone & Brattico, 2015). Comme indiqué dans le chapitre 1 (article 1), de nombreuses études se sont penchées sur les effets bénéfiques à long terme de la TMA sur les symptômes de la MA et ce, à différents stades de la maladie (Gómez Gallego & Gómez García, 2017; Prattini, 2016; Zhang et al., 2018).

3.2 Effets Limités de la TMA en MA : Lien avec les Réseaux Neuronaux Touchés

Bien que des améliorations aient été constatées dans l'état cognitif global, ainsi que dans les symptômes comportementaux et neuropsychiatriques, toutes les études ont indiqué que la capacité à effectuer les tâches quotidiennes ne s'améliorait pas. Gómez Gallego et Gómez García (2017) ont déclaré que la réhabilitation motrice et cognitive combinée pourrait être nécessaire pour améliorer le fonctionnement. Les effets limités de la TMA sur la fonction globale et le fait que la combinaison de tâches cognitivo-motrices pourrait aider semble relié au fait que les réseaux impliqués dans la cognition et la coordination visuomotrice sont altérés en MA (Verheij, Muilwijk, van der Cammen, Mattace-Raso & van der Steen, 2012).

3.3 Un Clavier Musical avec la TMA pour Rééduquer la Fonction en MA

L'utilisation du clavier musical co-conçu au chapitre 2 (article 2) et pour une TMA autonome va permettre des activités posturo-motrices supplémentaires par rapport à la seule TMA : par exemple, utiliser le clavier vertical nécessite des étirements des membres supérieurs, coordination et des mouvements rythmés du corps, contrôle de la posture pendant les perturbations générées par les mouvements. Le clavier permet aussi de stimuler deux fonctions cognitives épargnées et qui aideront à réactiver ou rééduquer les fonctions affectées : mémoire musicale (Jacobsen et al., 2015), et mémoire procédurale (van Halteren-van Tilborg, Scherder & Hulstijn, 2007), lesquelles permettront d'apprendre inconsciemment à la suite d'expositions répétées.

3.4 Aides Électroniques Adaptées à la MA et Implication des Utilisateurs

Le premier article mettait en exergue l'utilisation potentielle de dispositifs électroniques pour renforcer la participation autonome à la TMA. Même si la technologie fait partie de notre quotidien, les personnes âgées et les personnes vivant avec la MA peuvent trouver difficile à suivre le fonctionnement des nouvelles technologies (Bouchard, Imbeault, Bouzouane & Menelas, 2012). C'est notamment le cas, quand ces technologies n'ont pas été développées pour répondre à leurs besoins spécifiques. L'accessibilité et la maîtrise de cette technologie, aujourd'hui nécessaire, pourraient être facilitées, par exemple, en simplifiant les applications des tablettes électroniques ou en rendant l'utilisation des dispositifs plus intuitive (Boulay, Benveniste, Boespflug, Jouvelot & Rigaud, 2011).

De nombreuses recherches sont consacrées à la création d'aides à la mémoire électroniques ou à la technologie de loisirs pour cette population (Bouchard et al., 2012 ; Jamin, Luyten, Delsing & Braun, 2018; McGee-Lennon, Smeaton, Brewster, 2012), et la nécessité de concevoir des approches participatives (utilisateurs proactifs) est souvent soulignée. En effet, le dispositif électronique musical co-conçu dans cette thèse pallie le manque d'expérience technologique des utilisateurs avec MA et favorise leur participation active dans le processus de création musicale tout en activant leurs fonctions cognitives et motrices.

Conformément aux découvertes précédentes (Jury, 2016; McGee-Lennon et al., 2012), l'utilisation d'une approche de co-conception a permis de concevoir avec succès un prototype musical avec et pour les personnes atteintes de la MA. La solution développée favorise l'indépendance et ses caractéristiques sont toutes pensées pour la population ciblée.

Étant donné que la MA affecte chaque personne de différentes manières et à différents degrés, la conception avec cette population a nécessité que le chercheur/concepteur comprenne les capacités de chaque participant. Je voudrais donc souligner l'importance de mener un court entretien semi-structuré avec les participants avant le début de la session de co-conception. Dans le cadre de ce projet, cet entretien m'a permis d'évaluer superficiellement les capacités cognitives de chaque participant et d'adapter ainsi les techniques de co-conception. Il est également important de rappeler que, selon l'état de la personne âgée, il est souvent souhaitable que le participant apprécie séparément chaque petite partie de la conception, même si cela signifie qu'il n'aura pas toujours à l'esprit ou ne se souviendra pas de l'objectif final du projet.

De plus, l'utilisation de stimulus externes et d'aides, tels que les prototypes en papier, ont pu susciter la créativité et aider les limitations de l'expression verbale. Des études avaient signalé une telle importance des stimuli externes (Bourgeois & Mason, 1996; Hopper et al., 1998), mais nous avons constaté que, en demandant à l'utilisateur d'interagir avec le prototype en papier sans autre explication (par exemple, en lui demandant de simuler l'allumage du clavier), nous avons pu évaluer l'affordance du clavier, ce qui est particulièrement important pour assurer la manipulation intuitive.

3.5 Forces et Limites

À notre connaissance, la recension des écrits est la première revue consacrée exclusivement à la documentation des effets de la musicothérapie active sur la MA. Même si les études présentées ont trouvé des effets bénéfiques de la TMA sur les symptômes de la MA, une évaluation plus approfondie de la qualité de chaque étude doit être réalisée pour déterminer le niveau de preuve fourni par ces données. De plus, il est connu que les recensions des écrits concernant problématiques émergentes et complexes peuvent être biaisés en raison de différents biais cognitifs au moment de l'interprétation des sources. C'est pourquoi, alors que cette revue de la littérature permet de synthétiser les informations disponibles concernant la TMA dans la MA, des revues systématiques étudiant des résultats spécifiques devraient être réalisées afin de fournir un niveau de preuve plus élevé sur l'efficacité des interventions de TMA sur la MA.

La quantité des travaux disponibles concernant l'effet de la TMA sur le cerveau avec démence était limité et n'est donc pas suffisant pour consolider une théorie des mécanismes d'action de la TMA sur le cerveau avec MA. En fait, la pertinence de la TMA pour soulager les symptômes de la MA a été soulignée par de nombreuses études réalisées sur les effets bénéfiques de l'écoute de musique et du jeu des instruments de musique sur les structures et les circuits cérébraux reconnus comme étant affectés dans la MA.

En outre, nous n'avons pas trouvé aucune étude publiée rapportant une amélioration de l'autonomie fonctionnelle causée par la TMA. La littérature recommande l'utilisation de multiples modalités (telles que l'entraînement moteur et cognitif) pour améliorer l'autonomie fonctionnelle. Pour cette raison, des tâches d'entraînement moteur et cognitif ont été intégrées dans la conception de l'instrument et de la musicothérapie active. Cependant, des études futures impliquant l'utilisation du clavier conçu sur les personnes avec MA devraient être menées afin d'évaluer les possibles améliorations dans l'autonomie fonctionnelle.

À propos de l'utilisation d'une approche de co-conception, l'inclusion de plusieurs sessions individuelles avec des personnes avec MA, des groupes de discussion avec des proches aidants et des groupes de discussion avec des chercheurs de différents domaines, ont permis de collecter et de discuter des informations sous différents points de vue (triangulation). Cette approche de co-conception a donc permis d'augmenter la valeur de vérité, la neutralité, et la consistance dans l'étude. De plus, les données recueillies grâce à cette approche et à la recension initiale des écrits ont pu guider du processus de conception.

Des enregistrements audios et des notes ont été pris pendant toutes les sessions. Néanmoins, pour augmenter la valeur de vérité, l’utilisation d’un cahier pour prendre notes de terrain aurait pu faciliter la détection de tout biais de perception au cours du processus de recherche. Ceci est pertinent en raison de que la totalité du processus de recherche a été menée en français (la troisième langue de l'auteur), de sorte que les biais de perception auraient pu être fortement liés aux différences culturelles ou à l'anxiété lors de la communication en français.

Tout au long du processus de recherche, une attention particulière a été accordée à la compréhension des besoins, des exigences et des limites des personnes avec MA. Ce, afin d’adapter chaque partie du processus de conception pour qu’il soit le plus productif et engageant possible pour les participants. Des expériences de recherche précédentes avec des personnes de milieux très divers ont permis à l'auteur de répondre aux besoins des participants à ce projet, malgré le fait que ces besoins variaient considérablement d'un participant à l'autre.

En ce qui concerne le processus de recrutement, de nombreux facteurs ont joué un rôle important. D’abord, la plupart des participants potentiels ne souhaitaient pas participer, ce qui peut s'expliquer par l'apathie de nombreuses personnes avec MA de participer à une activité quelconque, et par la peur de ne pas être « musiciens » (même s'il était expliqué qu’il n’était pas une exigence). Deuxièmement, les limitations lors de la communication en français ont rendu difficile l'accès à certains participants potentiels, ce qui leur a fait perdre tout intérêt pour le projet. De plus, en raison de la vulnérabilité et des problèmes de santé mentale de cette population, l’accès aux personnes avec cette démence était très restreint.

Pour ces raisons mentionnées ci-dessus, le processus de recrutement a été plus long que prévu et le nombre de participants à la phase 2 du deuxième article a été de quatre au lieu des huit personnes initialement prévues. Néanmoins, l’inclusion de ces personnes dans le processus de co-conception a eu plusieurs effets bénéfiques : elles ont toutes contribué de façon importante à la conception du prototype en tant que partenaires au projet, donc sur un pied d’égalité avec les autres intervenants (écoute et prise en compte des commentaires et témoignages). De plus, Il est important de noter que le clavier co-conçu ne va pas remplacer d'autres thérapies pharmacologiques ou non pharmacologiques. Il est pensé comme un adjuvant aux traitements existants, pour les compléter et pour permettre une TMA autonome nécessitant une supervision minimale voire inexistante afin de bénéficier le plus souvent possible des effets bénéfiques de la TMA. Même si les interactions humaines sont bénéfiques et souhaitées (Cevasco, 2010), de nombreuses personnes avec la MA n'ont pas accès à des thérapeutes ou vivent seules, et la possibilité d'être autonomes en TMA grâce au clavier co-conçu leur ouvre de nouvelles possibilités d'amélioration fonctionnelle. En effet, parmi les quatre participants à la phase 2 (article 2), aucun n'avait jamais suivi de traitement non pharmacologique, deux vivaient seuls et deux vivaient avec leur conjoint.

Tous les participants à la phase 2 (article 2) étaient intéressés par le projet de recherche depuis le début, même s'ils étaient tous naïfs sur le plan musical. Néanmoins, d'autres participants potentiels qui ont été contactés ont indiqué qu'ils n'aimaient pas la musique ou qu'ils n'étaient pas intéressés par un tel appareil. Ainsi, le clavier musical pourrait ne pas attirer toutes les personnes avec MA. De plus, la plupart des tâches ont été conçues pour impliquer des utilisateurs naïfs ou peu familiarisés avec la musique. Par conséquent, les musiciens avec MA pourraient ne pas trouver les tâches aussi engageantes que les non-musiciens.

3.6 Recherches Futures

Le projet est encore en développement. En effet, le clavier et ses tâches musicales devront être toujours plus adaptées à l'expertise musicale et aux goûts musicaux des futurs utilisateurs.

Ainsi, raffiner davantage les exigences ciblées va nécessiter des études préliminaires sur l'utilisabilité, la fonctionnalité et les effets à plus ou moins long terme sur les symptômes cognitifs et moteurs de la MA. Une étude clinique à grande échelle pourra ensuite être menée afin de valider si l'utilisation du dispositif peut améliorer les symptômes des personnes vivant avec la MA.

Conclusion

Dans cette mémoire on a proposé un clavier musical électronique permettant aux personnes au stage léger de la MA de s'engager de manière autonome dans des sessions de TMA.

Ce clavier musical a été co-conçu avec succès avec la participation de personnes souffrant d'AM légère, des proches aidants, et de chercheurs. En outre, une recension des écrits sur l'utilisation de la TMA dans les MA a permis de guider le développement du processus de co-conception. L'article 1 (recension des écrits) a en effet examiné les effets et les limites de la TMA par rapport aux symptômes de la MA. Cela a également permis d'identifier différentes conditions pour susciter la participation à la TMA et promouvoir l'auto administration.

Sur la base des conclusions de l'article 1, il a été possible de créer un point de départ pour la conception du clavier musical et de la tâche musicale qu'il inclurait. Les résultats ont également permis d'orienter la conception tout au long du processus et d'aider à définir des stratégies de co-conception avec cette population.

Ce mémoire était limité à la conception du prototype. Des travaux supplémentaires sont encore nécessaires pour tester la portée des avantages possibles que l'utilisation du clavier peut avoir. Il est attendu que ce clavier électronique pourrait contribuer à atténuer les symptômes de la MA, d'une part en rapport avec les bénéfices de la TMA autonome et d'autre part en rapport avec l'intégration d'autres modalités thérapeutiques telles que la stimulation cognitive et l'activité physique. Également, le comportement et le bonheur exprimé verbalement par les participants à la phase 2 (article 2) lors du test de l'interface et de l'interaction avec les prototypes promet des effets positifs sur la santé mentale.

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Annexe A. Tableaux des participants dans les sessions de co-conception

Table 2 Tableau des caractéristiques des participants avec la MA

	Participant 1	Participant 2	Participant 3	Participant 4
Age	70	65	77	60
Sex	Male	Female	Male	Female
Mini Mental State Examination score	25	27	22	24
Marital status	Single	Married	Married	Single
Level of education	Master’s degree in statistics	CEGEP (nurse technician)	PhD in linguistics	Secondary school (In the Quebec scholar system)
Occupation	Retired	Retired	Retired	Unemployed and living on social assistance
Country of origin	Canada	Canada	England	Canada

Table 3 Tableau des caractéristiques des proches aidants

	Participant 1	Participant 2	Participant 3	Participant 4
Age	81	77	25	47
Relationship to the person with AD	Wife	Husband	Grandson	Daughter
Country of origin	Canada	Canada	Mexico	Iran

Table 4 Tableau des domaines de recherche des chercheurs participantes dans les sessions de co-conception

Participant	Research domain
1	Immersive and interactive installations aiming public awareness to the issues of disability and handicap, on the development of clinical tools, and the development of smart environments.
2	Human interaction deficiencies in presence or at distance, and devices that help compensate them.
3	Promotion, prevention and usage of technologies by people at risk of developing disabilities or presenting disabilities and loss of autonomy.
4	Early diagnosis of dementia and their pre-clinical and prodromal cognitive and psychiatric phases, as well as the treatment of neurodegenerative dementia using cognitive remediation / rehabilitation.
5	Brain adaptation (cerebral plasticity) in physiopathology and on neurostimulation as an approach to improve quality of life.
6	Human computer interfaces for art and rehabilitation.

7	Development and validation of tests to detect or diagnose language and cognition disorders associated with neurodegenerative diseases. Development and testing the effectiveness of therapeutic approaches, in which new technologies are used, to treat language and cognition disorders.

Annexe B. Tableau des taches de la session de musicothérapie et de l’ordre de présentation

Table 5 Tableau des taches de la session de musicothérapie et de l’ordre de présentation

#	Instructions	Section de la session
1	Avec une main, touchez la touche qui s’allume	Échauffement et familiarisation avec le clavier
2	Avec l’autre main, touchez la touche qui s’allume	
3	Maintenant, touchez les touches qui s’allument en utilisant vos deux mains	
4	Choisissez une chanson en la touchant avec votre doigt (Dans l'écran il y aura le titre de trois chansons) Vous avez choisi la chanson “___”. Si ce choix est correct, appuyez sur “continuer”. Sinon, choisissez une autre chanson.	Corps de la session
5	(La mélodie d’une chanson sera émise par le clavier) Touchez le titre de cette chanson avec votre doigt. (Si l’usager sélectionne la bonne réponse) oui ! le titre de la chanson est “___” (Si l’usager ne sélectionne pas la bonne réponse) en fait, le titre de la chanson est “___”	
6	Maintenant vous allez jouer cette chanson sur le clavier en appuyant sur chaque touche après qu’elle s’est allumée	
5	Répétition de la tâche #5	
7	Nous allons faire un exercice de mémoire. Une première touche du clavier va s’allumer et vous devrez la toucher. La même touche se rallumera, suivie d’une autre touche. Vous devrez alors toucher chaque touche dans l’ordre dans lequel elles se sont allumées. (Il y aura deux séquences de familiarisation avec trois touches chacune pour s’assurer de la bonne compréhension)	

5	Répétition de la tâche #5	
8	Maintenant nous allons faire un exercice d'attention. Vous allez entendre deux sons et vous devrez dire s'ils sont pareils ou différents en appuyant sur le bouton correspondant. (Deux boutons seront dans l'écran, un avec le mot "pareils" et l'autre avec la mot "différents")	
9	Écoutez le son de chacun de ces boutons et touchez celui qui a un son différent des autres. (Dans l'écran il y aura trois boutons qui s'allumeront et émettront un son un à la fois)	
10	C'est le temps de l'improvisation. Une mélodie sera jouée à l'arrière-plan. Touchez différentes touches du clavier pour jouer avec la chanson.	Fermeture de la thérapie

Annexe C. Feuillet d'information et formulaire de consentement pour les sessions de co-conception individuels avec des personnes avec la MA

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Feuillet d'information et Formulaire de consentement du projet de recherche

I. Titre du projet :

Conception d'un clavier musical pour entraîner les fonctions motrices et cognitives dans la maladie d'Alzheimer – objectif numéro 1 : co-conception individuel d'un clavier musical électronique.

II. Responsable et collaborateurs :

Responsable du projet : Ernesto Morales, Professeur adjoint, Département de réadaptation, Faculté de médecine, Université Laval et Chercheur régulier, Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIS)
Co-chercheurs : Cyril Schneider, Professeur en neurosciences, Département de réadaptation, Faculté de médecine, Université Laval et chercheur au Centre de recherche du CHUL.
Jocelyne Kiss, Professeure, Faculté de musique, Université Laval et chercheure au CIRRIS.
Étudiante: Sherezada Ochoa, étudiant à la maîtrise en sciences cliniques et biomédicales, Université Laval.

III. Introduction :

Nous sollicitons votre participation à un projet de recherche. Cependant, avant d'accepter de participer à ce projet de recherche, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce feuillet d'information et de consentement vous explique le but de ce projet de recherche, les procédures, les avantages, les risques et les inconvénients, de même que les coordonnées des personnes avec qui communiquer au besoin.

Le feuillet d'information et de consentement peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur responsable du projet et aux autres membres du personnel affectés au projet de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

La maladie d'Alzheimer (MA) entraîne une détérioration progressive du cerveau menant à un déclin neuro motrice. D'ici 2030, il est estimé qu'un million de Canadiens soit atteint par cette maladie. Notre projet de recherche s'intéresse à l'influence de la musicothérapie active (c'est-à-dire l'écoute et la reproduction de mélodies) qui inclut activité physique et cognitive sur la MA. Il a pour principal objectif la conception d'un clavier musical électronique simple (requérant une supervision minimale des proches dans son utilisation), proposant à l'utilisateur un programme évolutif d'exercices à compléter et capable de recueillir des informations sur le niveau de complexité des activités musicales et le temps passé à les réaliser. Il est prévu que le clavier soit surdimensionné pour obliger le déplacement et control motrice pour reproduire les mélodies.

Nous voudrions savoir si l'utilisation de ce clavier musical électronique, dans le cadre d'un programme de musicothérapie active, peut influencer le niveau d'excitabilité du cerveau des personnes atteintes de la MA. De plus, nous Nous sommes intéressés de savoir si telle situation peut contribuer à réduire l'intensité des symptômes cognitifs et moteurs, et à améliorer la qualité de vie des personnes avec cette maladie.

IV. Nature et objectifs du projet :

Notre projet de recherche poursuit les quatre objectifs suivants :

1. Conception d'un clavier musical électronique. Une méthodologie ancrée dans l'approche de co-conception (impliquant l'utilisateur final) sera employée afin de déterminer les caractéristiques du clavier (simplicité, programme d'exercices et capacité à recueillir des données sur le niveau de complexité et le temps accordé à sa réalisation) et veiller à ce que son utilisation soit agréable et favorise l'activité physique.
2. Construction du clavier musical électronique, dont certaines pièces nécessiteront l'emploi d'une imprimante 3D.
3. Tester l'utilisabilité, le fonctionnement et la facilité de son utilisation auprès de huit personnes sans incapacités dans le cadre d'une session de musicothérapie active de 45 minutes.
4. Mesurer pendant 3 mois l'influence des activités de musicothérapie active avec le clavier (entraînement de 4 semaines) chez 10 patients atteints de la MA légère sur leur excitabilité du cerveau, sur leur symptômes cognitif / moteur / fonctionnels, et sur leur qualité de vie.

V. Déroulement du projet :

Avant de commencer, pour s'assurer que vous rencontrez les critères cliniques cherchées pour le projet, l'équipe de recherche obtiendra, avec votre consent, l'information concernant votre diagnostic au dossier clinique. Les critères d'exclusion pour le projet sont: être musicien (savoir comment jouer une mélodie avec un instrument de musique) et avoir des troubles cognitifs ou moteurs non provoqués par la maladie d'Alzheimer.

Si vous rencontrez les critères cliniques cherchées pour le projet, vous participerez à la réalisation du premier objectif de notre projet de recherche. Pour ce faire :

Un membre de l'équipe de recherche vous convoquera à une rencontre individuelle de 120 minutes dans les locaux du Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIS). La séance sera enregistrée sur un support audio. La rencontre commencera avec une entrevue semi-structurée (date de naissance, personnes habitant avec vous, incapacités physiques et motrices, aide reçue de la part de vos proches, participations dans le cadre d'autres thérapies non-pharmacologiques).

La rencontre continuera en vous présentant le projet de recherche, le concept du clavier musical électronique et son fonctionnement. Vous serez alors invité à donner vos commentaires et vos propositions de modifications et d'améliorations concernant le clavier musical électronique, et ce, afin d'en assurer son attractivité et son confort dans son utilisation. Vous serez invité également à donner votre opinion concernant ses différentes caractéristiques (couleurs, boutons, dimensions, etc.)

Pendant que vous exprimez vos commentaires, nous réaliserons le dessin modifié du clavier musical comprenant vos propositions de modifications et d'améliorations. Ceci nous permettra de nous assurer que nous avons bien compris vos commentaires.

VI. Risques potentiels et inconvénients personnels :

Il n'existe aucun risque sous-jacent à votre participation au projet. Les inconvénients se limitent à vos déplacements au CIRRIS.

VII. Avantages possibles :

Feuillet d'information et Formulaire de consentement du projet de recherche

Vous ne retirerez aucun bénéfice personnel de votre participation à ce projet de recherche. Toutefois, les résultats obtenus contribueront à l'avancement des connaissances dans ce domaine.

VIII. Participation volontaire et retrait de la participation :

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en faisant connaitre votre décision au chercheur responsable du projet ou à l'un des membres du personnel affectés au projet. Votre décision de ne pas participer à ce projet de recherche ou de vous retirer n'aura aucune conséquence sur la qualité des soins et des services auxquels vous avez droit ni sur votre relation avec le chercheur responsable du projet et les autres intervenants.

IX. Clause de responsabilité :

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits ni ne libérez les chercheurs, le commanditaire ou les institutions impliquées de leurs obligations légales et professionnelles.

X. Indemnité compensatoire :

Vous recevrez une compensation monétaire de 20$ CA pour votre participation au premier objectif de ce projet de recherche.

XI. Confidentialité, conservation et utilisation des résultats :

À des fins de surveillance et de contrôle, le dossier de recherche peut être consulté par une personne mandatée par le comité d'éthique de la recherche de l'IRDPQ, ou par toute autre personne mandatée pour vérifier la gestion et le bon déroulement de la recherche.

Les renseignements recueillis demeureront strictement confidentiels dans les limites prévues par la loi. Afin de préserver l'identité des participants, ces derniers seront identifiés par un code. La liste des codes reliant les noms aux dossiers de recherche sera conservée par le chercheur responsable.

Tous les documents seront conservés dans un cabinet sécurisé et verrouillé dans le bureau du Dr Morales au Centre interdisciplinaire de recherche en réadaptation et en intégration sociale (CIRRIS).

Toutes publications scientifiques qui découleront de ce projet de recherche présenteront des données statistiques uniquement et en aucun cas le nom des participants ne sera publié ou divulgué à qui que ce soit.

Les données seront conservées pendant 5 ans suivant la fin du projet. Toutes les données, incluant les enregistrements audio, seront détruites après ces 5 ans.

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Institut de réadaptation en
déficience physique de Québec

Feuillet d'information et Formulaire de consentement du projet de recherche

XII. Questions sur le projet et personnes-ressources :

Si vous avez des questions liées au projet, vous pouvez contacter le responsable du projet, M. Ernesto Morales, par téléphone au 418 529-9141 # 6030 ou par courriel à ernesto.morales@fmed.ulaval.ca, ou l'étudiante à la maîtrise Sherezada Ochoa par courriel à sherezada.ochoa-echeverria.1@ulaval.ca.

Pour des questions d'ordre éthique, le participant peut communiquer avec la coordonnatrice du comité d'éthique de la recherche de l'IRDPQ au 418 529-9141, poste 2888 ou coordonnatrice.cer@irdpq.qc.ca. Indiquer que les frais d'interurbain seront remboursés sur présentation d'une pièce justificative, le cas échéant. Préciser également que pour les plaintes à formuler, le participant peut s'adresser à la commissaire aux plaintes et à la qualité des services de l'IRDPQ à l'adresse courriel suivante : plaintes@irdpq.qc.ca ou par téléphone au 418 529-9141, poste 6247 (téléscripteur ATS : 418 649-3734).

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Feuillet d'information et Formulaire de consentement du projet de recherche

Titre du projet : Conception d'un clavier musical pour entraîner les fonctions motrices et cognitives dans la maladie d'Alzheimer

Chercheur responsable du projet : Ernesto Morales

1) Le(la) responsable m'a informé(e) de la nature et des buts de ce projet de recherche ainsi que de son déroulement;
2) Le(la) responsable m'a informé(e) des risques et inconvénients associés à ma participation;
3) Ma participation à cette étude est volontaire et je peux me retirer en tout temps sans préjudice;
4) Les données de cette étude seront traitées en toute confidentialité et elles ne seront utilisées qu'aux fins scientifiques et par les partenaires identifiés au formulaire d'information;
5) J'ai pu poser toutes les questions voulues concernant ce projet et j'ai obtenu des réponses satisfaisantes;
6) Ma décision de participer à cette étude ne libère ni les chercheurs, ni l'établissement hôte de leurs obligations envers moi;
7) Je sais qu'aucune rémunération n'est rattachée à ma participation;
8) Le(la) responsable m'a remis un exemplaire du feuillet d'information et du formulaire de consentement;
9) J'ai lu le présent formulaire et je consens volontairement à participer à cette étude;
10) Je désire recevoir une copie des résultats de l'étude oui non
11) J'accepte d'être recontacté(e) pour d'autres projets menés par les chercheurs de ce projet oui non
12) Je consens à ce que mon dossier clinique soit consulté oui non

Nom du participant	**Date de naissance**	**Numéro de téléphone**
Signature du participant *	Date	
Nom du chercheur	Date	Signature

Annexe D. Feuillet d'information et formulaire de consentement pour les sessions de co-conception groupales

Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale
Québec
Institut de réadaptation en déficience physique de Québec

Feuillet d'information et Formulaire de consentement du projet de recherche

I. Titre du projet :

Conception d'un clavier musical pour entraîner les fonctions motrices et cognitives dans la maladie d'Alzheimer – objectif numéro 1 : co-conception groupal d'un clavier musical électronique.

II. Responsable et collaborateurs :

Responsable du projet : Ernesto Morales, Professeur adjoint, Département de réadaptation, Faculté de médecine, Université Laval et Chercheur régulier, Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIS)
Co-chercheurs : Cyril Schneider, Professeur en neurosciences, Département de réadaptation, Faculté de médecine, Université Laval et chercheur au Centre de recherche du CHUL.
Jocelyne Kiss, Professeure, Faculté de musique, Université Laval et chercheure au CIRRIS.
Étudiante: Sherezada Ochoa, étudiant à la maîtrise en sciences cliniques et biomédicales, Université Laval.

III. Introduction :

Nous sollicitons votre participation à un projet de recherche. Cependant, avant d'accepter de participer à ce projet de recherche, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce feuillet d'information et de consentement vous explique le but de ce projet de recherche, les procédures, les avantages, les risques et les inconvénients, de même que les coordonnées des personnes avec qui communiquer au besoin.

Le feuillet d'information et de consentement peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur responsable du projet et aux autres membres du personnel affectés au projet de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

La maladie d'Alzheimer (MA) entraîne une détérioration progressive du cerveau menant à un déclin neuro motrice. D'ici 2030, il est estimé qu'un million de Canadiens soit atteint par cette maladie. Notre projet de recherche s'intéresse à l'influence de la musicothérapie active (c'est-à-dire l'écoute et la reproduction de mélodies) qui inclue activité physique et cognitive sur la MA. Il a pour principal objectif la conception d'un clavier musical électronique simple (requérant une supervision minimale des proches dans son utilisation), proposant à l'utilisateur un programme évolutif d'exercices à compléter et capable de recueillir des informations sur le niveau de complexité des activités musicales et le temps passé à les réaliser. Il est prévu que le clavier soit surdimensionné pour obliger le déplacement et control motrice pour reproduire les mélodies.

Nous voudrions savoir si l'utilisation de ce clavier musical électronique, dans le cadre d'un programme de musicothérapie active, peut influencer le niveau d'excitabilité du cerveau des personnes atteintes de la MA. De plus, nous Nous sommes intéressés de savoir si telle situation peut contribuer à réduire l'intensité des symptômes cognitifs et moteurs, et à améliorer la qualité de vie des personnes avec cette maladie.

IV. Nature et objectifs du projet:

Notre projet de recherche poursuit les quatre objectifs suivants :

Feuillet d'information et Formulaire de consentement du projet de recherche

1. Conception d'un clavier musical électronique. Une méthodologie ancrée dans l'approche de co-conception (impliquant l'utilisateur final) sera employée afin de déterminer les caractéristiques du clavier (simplicité, programme d'exercices et capacité à recueillir des données sur le niveau de complexité et le temps accordé à sa réalisation) et veiller à ce que son utilisation soit agréable et favorise l'activité physique.
2. Construction du clavier musical électronique, dont certaines pièces nécessiteront l'emploi d'une imprimante 3D.
3. Tester l'utilisabilité, le fonctionnement et la facilité de son utilisation auprès de huit personnes sans incapacités dans le cadre d'une session de musicothérapie active de 45 minutes.
4. Mesurer pendant 3 mois l'influence des activités de musicothérapie active avec le clavier (entraînement de 4 semaines) chez 10 patients atteints de la MA légère sur leur excitabilité du cerveau, sur leur symptômes cognitif / moteur / fonctionnels, et sur leur qualité de vie.

V. Déroulement du projet :

Vous participerez à la réalisation du premier objectif de notre projet de recherche. Pour ce faire, vous serez invité à participer à une session collective de Co-Design de 120 minutes en compagne de cliniciens ou des proches de personnes ayant la Maladie d`Alzheimer. La séance sera enregistrée sur un support audio et aura lieu dans les locaux du Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIS).

Dans un premier temps, notre équipe vous présentera le projet de recherche. Elle vous dévoilera ensuite le clavier musical électronique conçu pour les personnes atteintes de la MA par le biais d'une présentation Powerpoint. Celle-ci comprendra le concept original de clavier musical électronique proposé, ainsi que les commentaires formulés par les personnes atteintes de la MA.

Ensuite, vous serez invité à formuler, sur la base de vos expériences avec des personnes atteintes de la MA, des commentaires, des questions et des propositions de modification ou d'amélioration au clavier musical électronique. Toutes les idées seront discutées et les meilleures conservées. Ceci permettra aux participants d'en venir à un consensus sur le concept et les caractéristiques du clavier musical électronique.

VI. Risques potentiels et inconvénients personnels :

Il n'existe aucun risque sous-jacent à votre participation au projet. Les inconvénients se limitent à vos déplacements au CIRRIS.

VII. Avantages possibles :

Vous ne retirerez aucun bénéfice personnel de votre participation à ce projet de recherche. Toutefois, les résultats obtenus contribueront à l'avancement des connaissances dans ce domaine.

VIII. Participation volontaire et retrait de la participation :

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en faisant connaitre votre décision au chercheur responsable du projet ou à l'un des membres du personnel affectés au projet. Votre décision de ne pas participer à ce projet de recherche ou de vous retirer n'aura aucune conséquence sur la qualité des soins et des services auxquels vous avez droit ni sur votre relation avec le chercheur responsable du projet et les autres intervenants.

Feuillet d'information et Formulaire de consentement du projet de recherche

IX. Clause de responsabilité :

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits ni ne libérez les chercheurs, le commanditaire ou les institutions impliquées de leurs obligations légales et professionnelles.

X. Indemnité compensatoire :

Vous recevrez une compensation monétaire de 30$ CA pour votre participation au premier objectif de ce projet de recherche.

XI. Confidentialité, conservation et utilisation des résultats :

À des fins de surveillance et de contrôle, le dossier de recherche peut être consulté par une personne mandatée par le comité d'éthique de la recherche de l'IRDPQ, ou par toute autre personne mandatée pour vérifier la gestion et le bon déroulement de la recherche.

Les renseignements recueillis demeureront strictement confidentiels dans les limites prévues par la loi. Afin de préserver l'identité des participants, ces derniers seront identifiés par un code. La liste des codes reliant les noms aux dossiers de recherche sera conservée par le chercheur responsable.

Tous les documents seront conservés dans un cabinet sécurisé et verrouillé dans le bureau du Dr Morales au Centre interdisciplinaire de recherche en réadaptation et en intégration sociale (CIRRIS).

Toutes publications scientifiques qui découleront de ce projet de recherche présenteront des données statistiques uniquement et en aucun cas le nom des participants ne sera publié ou divulgué à qui que ce soit.

Les données seront conservées pendant 5 ans suivant la fin du projet. Toutes les données, incluant les enregistrements audio, seront détruites après ces 5 ans.

XII. Questions sur le projet et personnes-ressources :

Si vous avez des questions liées au projet, vous pouvez contacter le responsable du projet, M. Ernesto Morales, par téléphone au 418 529-9141 # 6030 ou par courriel à ernesto.morales@fmed.ulaval.ca, ou l'étudiante à la maîtrise Sherezada Ochoa par courriel à sherezada.ochoa-echeverria.1@ulaval.ca.

Pour des questions d'ordre éthique, le participant peut communiquer avec la coordonnatrice du comité d'éthique de la recherche de l'IRDPQ au 418 529-9141, poste 2888 ou coordonnatrice.cer@irdpq.qc.ca. Indiquer que les frais d'interurbain seront remboursés sur présentation d'une pièce justificative, le cas échéant. Préciser également que pour les plaintes à formuler, le participant peut s'adresser à la commissaire aux plaintes et à la qualité des services de l'IRDPQ à l'adresse courriel suivante : plaintes@irdpq.qc.ca ou par téléphone au 418 529-9141, poste 6247 (téléscripteur ATS : 418 649-3734).

Centre intégré
universitaire de santé
et de services sociaux
de la Capitale-Nationale
Québec

Institut de réadaptation en
déficience physique de Québec

Feuillet d'information et Formulaire de consentement du projet de recherche

Titre du projet : Conception d'un clavier musical pour entraîner les fonctions motrices et cognitives dans la maladie d'Alzheimer

Chercheur responsable du projet : Ernesto Morales

1) Le(la) responsable m'a informé(e) de la nature et des buts de ce projet de recherche ainsi que de son déroulement;
2) Le(la) responsable m'a informé(e) des risques et inconvénients associés à ma participation;
3) Ma participation à cette étude est volontaire et je peux me retirer en tout temps sans préjudice;
4) Les données de cette étude seront traitées en toute confidentialité et elles ne seront utilisées qu'aux fins scientifiques et par les partenaires identifiés au formulaire d'information;
5) J'ai pu poser toutes les questions voulues concernant ce projet et j'ai obtenu des réponses satisfaisantes;
6) Ma décision de participer à cette étude ne libère ni les chercheurs, ni l'établissement hôte de leurs obligations envers moi;
7) Je sais qu'aucune rémunération n'est rattachée à ma participation;
8) Le(la) responsable m'a remis un exemplaire du feuillet d'information et du formulaire de consentement;
9) J'ai lu le présent formulaire et je consens volontairement à participer à cette étude;
10) Je désire recevoir une copie des résultats de l'étude oui non
11) J'accepte d'être recontacté(e) pour d'autres projets menés par les chercheurs de ce projet oui non

Nom du participant	**Date de naissance**	**Numéro de téléphone**
Signature du participant *	Date	
Nom du chercheur	Date	Signature