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**Editorial** 

# Chaos and order... Our world at a crossroads Ralph Spintge<sup>1,2</sup> & Joanne V. Loewy<sup>3,4</sup>

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As a scientific publication, we intend that our journal will not convey any political messages. However, at present it seems as if scientific expertise and experience is desperately needed to contribute insight and advice to secure the future of humankind in many aspects elaborated in part heretofore. We are at a crossroads leading to a future in chaos or can move back toward a state of order in peace. Let us try to see, if music may be a way to find possibilities for new directions to move toward.

Human life on earth as part of a developing universe is governed by one basic force: the interplay of Chaos and Order[1,2]. Chaos here is seen as a state of rhythmic disorder with little or no structure, order as a state of rhythmically controlled structure. Rhythmic processes over time do control our life on earth, such as change of day and night, summer and winter, and so forth. Life is governed by rhythms and oscillations providing flexibility and creative variability vital to our survival within threatening environmental changes. That rhythmically organized processes have oscillatory frequencies of a broad range. Even molecules, the smallest components of life functions, oscillate in their chemical and functional states<sup>3</sup>. At the same time, large social groups of human beings can be rhythmically synchronized and controlled in their behavior through music - as seen for instance in concerts or in functional use of military music.

At present quite a number of life processes are obviously moving from a state of order to a state of chaos. Fast growing chaos can be observed in various areas of life on earth:

- global climate change causing decrease in life expectancy also in so called developed countries<sup>4</sup>
- political crisis with a growing number of wars raging in all hemispheres causing migration of millions of people while the Cold War seems to have a comeback not only East - West, but also South - North
- sequence of increasingly threatening fatal pandemics (1999 West Nile Virus, 2003 SARS-CoV-1 Severe Acute Respiratory Syndrome, 2004 H5N1 Bird Flu, 2009/2010 H1N1 Influenza, 2012

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Ralph Spintge, MD Address: Department of Algesiology and Interdisciplinary Pain Medicine, Regional Pain Center DGS, Sportklinik Hellersen, 58515 Lüdenscheid, Germany. E-mail: Ralph.Spintge@hellersen.de | COI statement: The authors declared that no financial support was given for the writing of this article. The authors have no conflict of interest to declare.

MERS Middle East Respiratory Syndrome, 2014 Ebola, 2015 Zika Virus, 2019 SARS-CoV-2 Severe Acute Respiratory Syndrome Coronavirus Type 2 called COVID-19) with no end in sight<sup>5</sup>

- energy crisis increasingly spreading around the world
- food crisis of fast growing global impact culminating for instance but not exclusively in East Africa with hundreds of thousands of children starving to death

These name just a few examples, that threaten humanity's future with new attention as they seem to culminate all at the same time- challenging our capacity to adapt to such chaotic changes.

Music as a therapeutic intervention bringing back order to chaotic states in mind and body is well-established and frequently used in healthcare. This re-structuring capacity is stronger than in any other means of communication<sup>6</sup>. Rhythm in music has evidence-based impacts on rhythmic life processes governing vitality in human psychophysiology [3,7,8,9]. Basically, music brings order into chaos as it is a rhythmically structured sequence of metric, melodic, and harmonic units over time within a piece that interferes with structured sequences of events in other dynamic systems. That phenomenon is called entrainment [8], originally identified and named as "Relative Koordination" by a German scientist, Erich von Holst[7]. His concept describes that coupling of rhythms creates phase-relations, when complete synchronization is not reached, and superimposed amplitudes of different rhythms are added to or subtracted from each other leaving their phase coupling unchanged. This way even human behavior as a dynamic system can be influenced by external rhythmic stimuli. Social systems like entire societies are also dynamic systems underlying such rules[2,10]. Is it possible that entrainment effects can happen even in political behavior? Why not, as demonstrated in military music, political songs, functional music used to enhance messages in audiovisual media, and so forth. So, how can we use that specific capacity of music to change political erratic behavior, enable peace talks, as well as serious negotiations and actions on climate and

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hunger, and so forth? We think that Music Therapy today has a much broader realm of responsibility beyond health care. Consequently, We assume that music may help us cope with those chaotic situations threatening presence and future of mankind mentioned above. A global orchestra of common sense against Chaos. All Music Medics and Music Therapists are called upon to join forces, cross (political) borders and give one another impulse for mutual understanding and peace using their/our expertise in providing structure and order counteracting Chaos in individuals and societies as well. The world is at a crossroads, let us help to move us into the right direction. In that sense, composition of this issue is yet another example for crossing borders, exchanging messages and concepts, theories and data, in order to move from Chaos to Order for a better world.

Our journal opens with the ingenuity of three nurses in Storytelling Through Music to Facilitate Meaning Reconstruction and Address Psychosocial Stress in Oncology Nurses. Authors Carolyn Phillips, Deborah Volker, Barbara Jones address the uncomfortable reality that so many of our frontline healthcare workers' are exposed to significant suffering and loss, which often can result in depression. Their study evaluates post-intervention qualitative data from their study participants and uses content analysis to reveal some significant themes.

In the next article Jenna Schlorff, Brandon Ruan, Tiffany Got, and Chelsea Mackinnon show how music engagement and intergenerational programming may improve depressive symptoms and reduce social isolation in seniors through an innovative new program. In *Understanding the impact of the "Fountains of Uke" Intergenerational Music Program on Long-Term Care Residents*, readers will be inspired to learn how musical experiences with intergenerational interactions can foster relationships and engagement.

Moving to the younger generation and focusing on the immediate needs affecting children and families, a timely procedural music therapy article follows. Care, Compassion, & Controversy: Supporting Children in a Covid-19 Vaccine Pod through Music Therapy & Child Life outlines authors John Mondanaro and Jessica Sturgeon's Covid-19 vaccine pod support. Their approach synthesizing a music therapy and child life strategies shows practice efficacy supporting children, their personal caregivers, and observable benefits, as well, for the nursing staff administering the vaccine.

It is always a welcomed feature of our journal to have interdisciplinary focus. One such discipline that crosses a myriad of populations, but in particular those with dementia, is speech-language therapy. Linda Carozza, an experienced clinician generously presents assessment considerations by reviewing many of the pertinent tools available to practitioners. Using a world view lens, in *Perspectives on Dementia from a* 

Speech-Language Pathologist: An interdisciplinary focus she emphasis the details of assessing and how strong evaluation may lead toward creative expansion and a broadening of treatment options.

In recognizing that neglect is a often seemingly insurmountable problem in healthcare, both in access and in designing treatment strategies, Andrew Danso, Mikaela Leandertz, Esa Ala-Ruona & Rebekah Rousi presents *Neglect, Virtual Reality and Music Therapy: A Clinical Report.* Based on his interesting review of evidence exploring intersections of virtual reality and music therapy, interventions with the purpose of understanding and addressing neglect rehabilitation in stroke recovery is considered. His literature analysis reflects initial promising findings for symptom reduction during neglect rehabilitation through the use of VR and Musical Neglect Training interventions.

Timos Papatzikis provides an overview of the 7<sup>th</sup> International Association for Music and Medicine conference. This conference occurred in Athens in June and was attended in-person by doctors, nurses, music therapists, neuroscientists, reseachers and clinicians from around the globe. A month of virtual lectures, workshops and Special Interest Groups followed on virtual platforms.

Finally, Aksana Kavaliova provides a detailed book review of co-Editors Amy Clements-Cortes and Joyce Yip's new 2021 text *Relationship Completion in Palliative Care Music Therapy* published by Barcelona Publishers: Dallas, Texas. Kavaliova is generous with her descriptions of topics and the review highlights the many pertinent themes of this informative work.

As always, we invite you to submit your writing as we prepare for a full rest-of the Summer and Fall. Whether a new and innovative study, a clinical report, case study or theoretic conceptual article, we hope our journal motivates you to share your work. Our readership continues to grow and the topics and themes ignite insights worth sharing with our global community.

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Full-Length Article

# Storytelling through music to facilitate meaning reconstruction and address psychosocial stress in oncology nurses

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#### Abstract

Frontline healthcare workers are exposed to significant suffering and loss. Recent studies have shown increased rates of depression among nurses and physicians [1], and increased rates of suicide in nurses compared to the general population [2]. Few clinician well-being interventions focus on increasing the awareness and expression of clinician's emotions to improve psychosocial well-being. In particular, nurses are at the forefront of cancer care, and studies indicate that they cope with work-related emotions in isolation. Storytelling Through Music is a 6-week intervention that combines storytelling, reflective writing, songwriting, and stress management skills. The parent study was a quasi-experimental design, with 43 oncology nurses in either the intervention group or a non-randomized comparison group. This study evaluates the post-intervention qualitative data from participants in the intervention group (n=22). Content analysis was used for analysis, which revealed the following themes: belonging, finding meaning, and emotional transformation. Participants reported learning they were not alone in the emotional experience, that they were reminded of why they work in oncology, and that hearing their story in song transformed their feelings from sadness to something beautiful. Further, they described that hearing their story reflected back to them in song was deeply moving and provided them with emotional insight.

Keywords: professional grief, psychosocial stress, meaning, music intervention, burnout

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#### Introduction

Prior to the COVID-19 pandemic, burnout and compassion fatigue rates were rising among healthcare workers (HCWs) [3,4]. Currently, increasingly, front-line HCWs face unprecedented mental health challenges and are at significant risk for long-lasting psychological trauma as a result of the COVID-19 crisis [5,6]. Psychosocial stress in the workplace is complicated, and the surrmounting adverse effects have a detrimental impact on the well-being of HCWs and, in turn, patient outcomes [6,7]. Burnout and compassion fatigue can result from systemic workplace problems and unaddressed psychosocial and emotional stress [3,7].

Professional grief is one component of psychosocial and emotional stress that confronts HCWs [8], yet little attention

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has been paid to helping HCWs understand their work-related grief and how to cope with it. Much of the literature examining how oncology nurses cope with work-related emotions suggests that they cope in isolation [9-11]. Papadatou and colleagues (2002) found that HCPs also avoid their emotional experience. They noted that HCPs fluctuated between experiencing and avoiding grief, with most HCPs avoiding grief, which resulted in various burnout levels. Twenty years later, there are few tools to help HCW cope with their work-related emotions, particularly professional grief.

One way oncology nurses positively cope with patient death is by finding meaning in their work [12]. Holland and Niemeyer (2005) found that HCWs coped more effectively with repeated exposure to death when they were able to integrate and modulate these experiences through a broader meaning-making framework or spiritual worldview. Research suggests that when bereaved caregivers make meaning of their caregiving and bereavement experiences, they may exhibit lower depression and anxiety [14]. Studies also suggest that, when allowed to tell personal stories of caregiving and death, bereaved caregivers can understand the purpose of these events in their life, and are thus able to make meaning of these experiences [15-17]. Research on storytelling's psychological

and emotional benefits has shown that the process of developing a story and sharing it with others in a safe and supportive environment may reduce depression and anxiety among caregivers [18,19], as well as increase their connections with others who share a similar experience, reduce isolation, and potentially increase social support.

Songwriting is a method used by some music therapist to help people explore grief, loss, and trauma through the exploration of narrative and has been shown to be useful in providing emotional insight, expression, and finding meaning [20-22]. Music therapists employ numerous strategies for lyric creation [23]. Story-songs is a specific technique created by Loewy and Rubin-Bosco (20, 24) to aid adolescents in a creative exploration of their traumatic experience to find musical and emotional resolution. Loewy (20) also created the Song Sensitization method to provide clients with an opportunity to safely share and engage with their story in a safe creative process.

The purpose of this study was to explore the postintervention qualitative findings from a larger pilot study that evaluated the feasibility and effect of the intervention, Storytelling Through Music, to help oncology nurses cope with their worked related emotions. A preliminary analysis of this research was presented in Abstract form at the International Association of Music and Medicine conference [26].

#### Material and Methods

The parent study was a feasibility study that employed a two-group quasi-experimental design utilizing multiple methods of data collection and analysis. Approval to conduct the study was obtained through a university institutional review board (2018-05-0061). This paper reports the qualitative data from participants in the intervention group (n=22) with analysis focused on participants' perception of using "Storytelling Through Music" to address work-related emotions. Qualitative data was collected immediately after intervention participation and one-month later.

#### Sample and Setting

Convenience sampling was used to recruit 43 oncology nurses throughout Central Texas to the parent study [27]. Twenty-two participants were in the intervention group, and data from only this group is reported. Potential participants were primarily recruited through the local oncology nursing professional organization, but also through presentations at local hospitals and outpatient cancer clinics. Inclusion criteria included: oncology nurses over 18 years of age, able to read and speak English, who had worked in oncology for at least one year, or

they had worked in oncology within the past five years if not currently in oncology. Oncology nurses were excluded if their role did not include direct patient care.

#### **Storytelling Through Music Intervention**

A full description of the intervention can be found in a previous publication [27]. In summary, the Storytelling Through Music intervention is a 6-week intervention combining storytelling, reflective writing, songwriting, and stress management skills. During the first four weeks, participants meet weekly for approximately one to one-and-a-half hours. The meetings began with a 10-minute stress management (guided breathing, meditation, body scan, and self-compassion) skills teaching provided by the intervention facilitator. No music was used during the teaching of the stress management skills, but each session ended with the group singing a cappella to a Loving-Kindness meditation. The writing sessions were guided with writing prompts (e.g., describe a memorable caregiving experience) to assist the participants in writing their caregiving stories. Once the caregiving stories are written, during the fifth week, participants meet with a songwriter, who creates a song from their caregiving story.

This method is similar to "Playback Theatre" [28] in that the songwriter creates and plays back a song that reflects the participant's story. It is different from "Playback Theater" in that the other participants in the group do not play a role in reflecting back the other participants stories. The songwriters were professional singer-songwriters located throughout the United States. All songwriters participated in a 2-hour orientation that was led by intervention facilitator. The majority of the songwriters played the acoustic guitar, but two songwriters played the piano. At the end of the fifth week, there was a live performance of the stories and songs. Each participant read their story and then the songwriter followed their story with a performance of their song. The last week of the intervention concludes with a final writing session to debrief and provide closure for the participants.

#### **Data Collection**

Individual Factors. An information sheet was used to collect background data (age, education, race, ethnicity, marital status, employment, number of years in nursing, number of years in oncology, additional certifications, etc.) to describe the sample (see Appendix A).

Qualitative Questionnaire. Participants' experience and perception of the intervention were captured from a series of open-ended, qualitative questions asked immediately after

completing the intervention and 1-month post-intervention (see Appendix B).

#### **Data Analysis**

Descriptive statistics were used to describe the sample characteristics. Conventional content analysis was used to analyze the qualitative data. This analysis method is appropriate when little is known about the experience being studied [29]. The analysis flows using inductive coding methods [30] instead of being driven by pre-conceived categories. In vivo coding methods, which entails using words or short phrases from the participants' own language [30], were used to derive the first cycle of codes from the open-ended questions. Then from that list of codes, the second layer of coding—pattern coding—was used to create a smaller number of categories [30]. To improve the credibility and trustworthiness [31] of the analysis, the first (CP) and second (DV) authors independently reviewed the qualitative data and generated the initial set of codes. Then they met to discuss the initial codes and sought resolution where there was discrepancy. The final coding was reviewed by all three authors (CP, DV, and BJ). All three authors are experts in qualitative data analysis. Throughout the study, an audit trail of coding and decision-making was maintained to promote credibility and dependability [31]. For this analysis, only the open-ended qualitative data was analyzed. A musical analysis was not conducted.

#### Results

The demographic characteristics of the sample are described in Table 1. A total of 22 oncology nurses participated in the intervention [mean age: 39.7 years (SD=11.5; range = 25-65 years)]. They were primarily female (91%) and white (100%), and 27% self-reported as Hispanic. Three themes emerged from the post-intervention, qualitative data: Belonging, finding meaning, and transforming emotions to reveal how storytelling through music helped oncology nurses cope with work-related emotions. Each theme is discussed in detail below.

**Table 1**. *Demographics and Workplace Characteristics (N=22)* 

Characteristics	Mean	SD
Age	39.7	11.5
Years of Nursing Experience	11.8	10.7
Years of Oncology Nur Experience	rsing 8.6	9.0

Characteristics	Category	n
Gender	Female	20
	Male	2
Race	White	22
Ethnicity	Non-	16
·	Hispanic	6
	Hispanic	
Highest level of Nursing Education	Associate's	4
	Bachelor's	17
	Graduate	1
Employment Status	Full-time	21
	Part-time	1
Working in Oncology (currently)	Yes	21
	No	1
Patient Setting	Inpatient	1
-	Outpatient	19
	Other	2
Patient Population	Adult	19
_	Pediatric	3
	Both	0
Certifications	Yes	12
	No	10
Formal Education about Self-care	Yes	7
	No	15
Self-care CEU Attendance	Yes	4
	No	18
Workplace Bereavement Support	Yes	4
Programs	No	17

#### Belonging

The theme of "belonging" is explained by three sub-themes: not alone in feelings of grief, collective suffering in isolation, and shared healing through common humanity. The majority of participants remarked that sharing their emotions about their caregiving experiences with other nurses was unfamiliar, but rewarding. They learned that their peers had similar emotional experiences, which lessened their isolation and strengthened feelings that they shared a common humanity. One participant stated, "Joy, remembrance, happiness, healing. I felt comforted by the collective shared experiences that other nurses wrote about. They were similar in some form and reminded me that we often need more emotional support for ourselves and for others than we tend to believe."

Another stated, "It was helpful hearing that I am not the only nurse in this arena of nursing who suppresses my feelings of grief. Letting it out verbally and through song was cathartic."

Others commented on feeling more connected to their coworkers, "I always knew this was an emotional job, but it did help to hear from my co-workers that they not only understood my feelings but they shared the same." Another said, "I feel more open and connected with my co-workers."

#### **Finding Meaning**

The second theme that emerged through the qualitative data was "finding meaning." This theme builds on the first theme of belonging because participants found meaning in their connection with their peers, which changed how they wanted to interact with their peers and patients in the future. One participant stated, "I hope to be able to mentor my younger coworkers to take the time to savor and record their experiences. Encourage them to share their stories with me." Another stated, "I've been reminded of the values I wanted to hold as a new nurse and how to incorporate those back into my nursing practice. I've learned that everyone has a story and that I must remember to be respectful of them."

The theme of "finding meaning" evolved from writing their stories to hearing their stories in song. Some participants described that they were reminded of the meaning they derive from their work through the writing. For example, one participant said, "When patients come to say good-bye, or they walk out, and we know they are dying, we do not have time to grieve. We do not have time to honor the patient and their journey. This writing gave me that opportunity, but it also helps me see why I continue to do what I do. It's the patients and their journey and what they teach me along their way."

Participants also remarked that writing, as a form of emotional expression, was also meaningful. One stated, "Being able to sit quietly and write. I find writing a purifying way to purge the thoughts and emotions that fill my mind on a daily basis, but rarely have the time. I enjoyed the purposeful moments taken to encourage this purge." Another commented on both the writing and the shared experience, "The fact that it forced me to write about and discuss these feelings. And sharing them with peers with whom I work helped me feel less isolated and I enjoyed getting to know the other nurses."

Participants described the song as providing new insight and sometimes new meaning to their stories. One participant said, "I heard things about my experience that I had not previously noticed or understood." Another said, "Without the song, I wouldn't have seen the beautiful side of my story. The songwriter captured things that I hadn't recognized before."

### **Transforming Emotions**

The third theme that arose from the post-intervention qualitative data was "transforming emotion." Participants described emotions being transformed through each phase of the intervention. For example, one participant said she "watched [her] despair turn into hope through writing,

storytelling, and music." Another said, "... Now I think about it when I'm having a hard emotional time and remind myself of the story. It was cathartic each time I sang it with the music."

There were many comments about recognizing and honoring emotions. For example, one participant said, "Coping mechanisms, changing the way we talk about our suffering, accepting my feelings without judgment." Another stated, "I've learned to give myself grace and forgiveness." Another example of the emotional transformation is illustrated in this quote, "My soul had become somewhat numbed to all the pain and devastation that I see daily in my workplace. This program helped bring back my kindness and empathy."

One participant discussed how the song helped transition a sad story to a positive memory and that specific lyrics have become a tool to help her through hard days. She said, "I fell in love with the song and memory more and more each time I listened to the song. I became joyful about my experience with [the patient] instead of saddened by her loss. The lyrics to the song would stick in my head for hours, or even days at a time, and encourage me throughout false beliefs I have had about myself in the past. For instance, the line "time to listen to me" has continued to encourage me to tune in with my emotions and thoughts, use them or release them as needed, and practice self-care and love mentally and emotionally."

Finally, in addition to transforming their work-related emotional experiences and expression, some participants also described a transformation in their emotional expression in their personal lives, which resulted in more genuine conversations, communication, and connection. Specifically, some participants remarked that they felt more emotionally open with their spouses. One participant said, "I am more willing to share my sadness with my husband instead of suppressing it. He loves that I have shared some of this process with him. Brought us closer as a couple." Another remarked, "I've uncovered a story and emotions that I need to express to the rest of my family so that they don't stay bottled up for another 20 years." This participant went on to say, "I've also found myself more willing to open up about my story. So far, I have shared it with my husband and good friend, both of whom stated they were very glad to have learned more about me."

#### Discussion

Findings from this analysis suggest that oncology nurses who participated in the Storytelling Through Music intervention found belonging, meaning, and emotional transformation by sharing their caregiving stories with their peers and working with songwriters to create songs from their stories. The oncology nurses expressed emotions of sadness, despair, and grief in their caregiving stories. By telling their stories through

music, they could transform their emotions to see the beautiful side of their stories, find meaning, and embrace their emotional experience without judgment and in the company of the peers who understand the grief that can accompany caregiving in oncology.

In 2000, Papadatou created the Model of Health Professionals' Grieving Process, which was influenced by the Dual Process Model of Coping and Bereavement [32] and conceptualized HCPs' reactions to cumulative patient deaths [33]. It suggests that grieving is personal, but also influenced by a social-interactive process. It incorporates a fluctuation between avoiding and experiencing grief, which allows the professional to attribute meaning and ultimately transcend loss [33]. Findings from this study suggested that participants constructed meaning together as they allowed themselves to share their stories authentically and as the songwriters crafted their song reflecting back their stories in music.

Adwan (34) utilized the Model of Health Professionals Grieving Process as the conceptual framework to explore the relationships between pediatric nurses' (N=120) self-reported and measured grief experiences to burnout and job satisfaction. They found that nurses experience grief over patient death in similar ways to family caregivers. However, the intensity of grief reflected on the grief scales was less than the levels found in family caregivers from the scale validation study. Their findings suggest that the interaction between the nurses' grief, burnout, and job satisfaction is dynamic, and there is a need for grief interventions [34].

We learned in our work that interventions that address deeply held emotions must be delivered with caution and in a safe space [35]. It was essential to teach self-care skills during the writing sessions to help participants tell their stories. At times, emotions were intense during the writing and sharing of stories. To prevent secondary trauma in the group setting, we defused the emotions with the self-care skill we learned that session. These "in the moment" experiences provided good opportunities for the participants to practice self-care skills in intensely emotional settings. In those moments, we helped them learn to feel their emotion and actively cope with them through breathing, mindfulness, and self-compassionate thoughts, instead of avoiding their emotions.

Historically, the mental health of HCWs has remained a silent topic. Qualitative studies analyzing nurses' grief have asked how many nurses received grief education in their formal training or on the job. The studies that proposed this question reported that very few nurses received any such training [35-40]. Aycock and Boyle (40) found that 45% of nursing respondents did not receive education or skill-development opportunities that addressed work-related coping. Currently, medical and nursing education systems are failing to educate their students about professional grief. The culture

surrounding emotional and mental well-being of HCWs must change, and healthcare practitioners' education is the first opportunity to influence culture.

The data from this study were collected before the COVID-19 pandemic. Over this past two years, the amount of suffering and death that nurses have been exposed to is unprecedented [3-4]. In addition to the need for more interventions to address professional grief, there is also a need to measure this construct. Many other measures (moral distress, compassion fatigue, burnout, secondary traumatic stress) are currently being used to measure nurses' and other HCWs' emotional experiences, and they are appropriate for some situations. However, the effects of the COVID-19 pandemic have heightened the need to also address professional grief.

#### Limitations

Study limitations include small sample size and the use of convenience sampling. With this sampling method, it is possible that participants in the study do not represent the general nursing population. The sample in this study was also homogenous and overly represented by outpatient oncology nurses rather than inpatient. Future studies should aim for more diverse sampling to understand generalizability.

#### Conclusion

Nurses who work in oncology have few opportunities to reflect on the impact caregiving has on the self. Storytelling Through Music provided a setting for these nurses to discuss their emotions with their peers, thus providing a community and an opportunity to learn that they are not alone, which served their capacity to find meaning, and transform their emotional experience. Future research is needed to foster interventions that address professional grief in order to maintain a healthy and robust healthcare workforce. Further, opportunities to educate future HCWs is also needed. If HCWs are expected to give care that utilize their emotions, we must teach them how to cope.

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## Appendix A

## **Background Information**

 $(Timing: O^1)$ 

	(11ming: O)	
1.	What is your preferred method of communication? (please check your #1 preference but list all options)	
	Text:	
	Email:	
	Phone:	
2.	What is your age?	
3.	What is your race? Asian	
	Black or African-American	
	Native Hawaiian or other Pacific Islander	
	Native American or Alaska Native	
	White	
	Mixed race	
4.	What is your ethnicity?	
	Hispanic or Latino	
	Not Hispanic or Latino	
5.	What is your marital status?	
	Single	
	Married	
	Long-term relationship, unmarried	
	Divorced	
	Widowed	
6.	Highest level of nursing education?	
	Associate's Degree	
	Bachelor's Degree	
	Diploma	
	DNP	
	Master's Degree	
	Other	

## PhD/DNSc Degree

7.	Highest level of other education? Associate's Degree Bachelor's Degree Master's Degree Doctoral Degree
8.	Years of Nursing Experience?
9.	Years of Oncology Nursing Experience?
10.	Employment status? Full-time Part-time Retired Unemployed
11.	Are you currently working in oncology?  Yes  No  If not, what caused you to leave oncology?
12.	What is your current practice setting? Inpatient Outpatient Other
13.	What is your primary patient setting?  Adult  Pediatric  Adult and Pediatric  N/A
14.	What is your specialty?  Bone Marrow Transplant  Medical Oncology  Palliative Care  Radiation Oncology  Surgical Oncology

No (please explain)

	Non-oncology
	Prevention/Detection
	Other
15.	What certifications do you hold?
	OCN
	AOCNP
	AOCNS
	AOCN
	End of Life Nursing Education Consortium (ELNEC)
	None
	Other
16.	Did your nursing education teach you how to care for yourself while caring for others?  Yes (please explain)  No (please explain)
17.	Have you attended any CE programs about self-care for the caregiver? Yes (please explain) No (please explain)
18.	Do you feel your workplace has sufficient staff support and/or programs in place to effectively deal with work-related emotions that you experience around patient death?  Yes (please explain)

## Appendix B

# Storytelling Through Music Evaluation: Immediate Post $(Timing: O^3)$

( ......

Vriting Workshop:		
Do you feel like you had er	nough time to write your story? (please mark a	an "X" on the line)
0	5	10
Not enough	Just enough	Too much
Tell me about your emotio	nal experience of writing your caregiving stor	y?
Did you read your story ou	at loud to the group?	
Yes (please explain) No (please explain)		
Do you think that sharing	out loud with the group was beneficial? Please	e explain.
Yes (please explain) No (please explain)		
ngwriting Portion:		
Did you have enough time	to work with your songwriter?	
0	5	10
Not enough	Just enough	Too much
not, how would you have s	tructured your time with them differently?	
Did you find it useful to ch	neck back in with the songwriter to check your	song for accuracy?
0 Not useful	5	10 Very Useful
1.00 400141		. ory oscial
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0 Uncomfortable	5	10 Very Comfortable
8. Do you feel like the songwriter capt	tured your story in your song?	
0 Not at all	5	10 Perfectly
If not, please explain.		
9. How did it feel to hear your story p	ut to music?	
10. Please tell me about your experien	ace sharing your story and song in	performance with your cohort.
General:		
	process your work-related emotion	ons?  10 Very helpful
11. Was this program a helpful way to  0		10
11. Was this program a helpful way to  0  Not helpful	5	10 Very helpful
11. Was this program a helpful way to  0  Not helpful  12. What have you learned through th	5 nis program that you intend to car	10 Very helpful
11. Was this program a helpful way to  0 Not helpful  12. What have you learned through the 13. What has been the impact of particular particul	5  nis program that you intend to car cipating in this program on your p	10 Very helpful ry forward in your career?
Not helpful  12. What have you learned through th  13. What has been the impact of partic	5  nis program that you intend to car cipating in this program on your program	10 Very helpful  ry forward in your career?  professional life? What has changed for you?

<ul><li>☐ Yes, probably. (please explain)</li><li>☐ No (please explain)</li></ul>	
Future Programming:	
17. What other suggestions do you have for future programming?	
$-\frac{N}{2}$	MMD   2022   14   3   Page 151

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#### Full-Length Article

# Understanding the impact of the "Fountains of Uke" intergenerational music program on long-term care residents

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#### **Abstract**

As the aging population reaches an all-time high, depression and social isolation among older adults are becoming significant concerns for public health. Music engagement and intergenerational programming may improve depressive symptoms and reduce social isolation in seniors by fostering relationships and engagement. Thus, the "Fountains of Uke Program" combines musical experiences with intergenerational interactions to combat these outcomes by creating a space where elementary students and Long-Term Care residents can engage in music and social interactions. This study aims to investigate the program's effects on residents in Long-Term Care homes. Behaviour, cognition, depression, and social isolation were measured before and after the intervention using validated scales and qualitative interviews. Quantitative measures did not show improvements in the outcomes of depression and social isolation. However, qualitative outcomes indicate the intergenerational music program had positive impacts on the Long-Term Care resident participants. Future studies should be implemented over a longer time period, in multiple Long-Term Care homes, and with a larger sample size to increase external validity. Future research should also consider the baseline health status of participants, as well as the normative mental and physical health decline among Long-Term Care residents over time when selecting outcome measures, analyzing data, and drawing conclusions.

Keywords: Intergenerational; music, older adults; depression; Long-Term Care

Multilingual abstract | mmd.iammonline.com

#### Introduction

As the population ages, depression and social isolation among older adults have become significant public health concerns [1]. Social isolation is associated with negative health outcomes, including worsened self-rated physical health, depressive symptoms, cognitive decline, higher rates of rehospitalization, and increased risk of mortality [1].

Intergenerational programming, such as the "Fountains of Uke Program" (FUP), can assist in alleviating social isolation by providing a secure environment to develop relationships between Long-Term Care (LTC) residents and young children. Fostering and promoting intergenerational relationships

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enables the exchange of knowledge and experiences between generations [2]. These exchanges are beneficial to both parties: LTC residents are able to stay updated and aware of current social issues; children are able to develop a positive perception of adulthood [2]. The participatory arts such as music can be used as a vehicle to facilitate intergenerational engagement among residents in LTC settings [2]. Using music as a tool of engagement in LTC settings has demonstrated enhanced social interaction between LTC residents and strengthened relationships towards LTC staff.

The purpose of this study is to investigate the use of a structured intergenerational music program, the FUP, in a LTC setting. It is hypothesized that the FUP will decrease social isolation and increase cognitive and socially-appropriate behaviours of participating LTC residents.

#### Methods

This non-randomized, convenience cross-sectional study involved residents from one LTC facility located in Hamilton, Ontario, Canada. Behaviour, cognition, depression, and social isolation were measured before, during, and after the FUP intervention [3]. The staff at the LTC home identified residents

who met the eligibility criteria. Both male and female participants were included. Residents who had previously participated in the FUP were only included after a six-month washout period [4]. Individuals with dementia were eligible to participate in this study. The clinical judgment of the nursing and program staff was used to determine which residents were capable of providing consent to participate in the research project. For residents who were deemed not capable of providing informed consent, their Power of Attorney for Health Care was asked to provide consent on their behalf. Data was collected pre- and post-intervention using the Cornell Scale for Depression, the Hawthorne Friendship Scale, and four subscales of the Resident Assessment Instrument (RAI). Researchers also facilitated an open discussion with residents to obtain qualitative data and feedback about the program during post-intervention data collection. Questions regarding music and the FUP were asked to prompt discussion about past memories and to gather details regarding the residents' experiences during the program.

#### **Ethics**

Ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB-3119).

## Description of Fountains of Uke Program Sessions

The Fountains of Uke Program (FUP) was utilized to facilitate relationship formation between elementary school children and LTC residents through engagement with music. The paper by Pieris [5], and Justin et al. [3], explains the theory and structure of the FUP. The program aims to promote self-confidence, happiness, and well-being to residents, along with a sense of connection and the opportunity to form relationships [3, 5]. The program facilitators were upper year McMaster Students who were enrolled in a course that explored the importance of intergenerational relationships and music. The course instructor was not a music therapist but has significant experience working in the field of music, with young students and older adults.

The study period was twelve consecutive weeks, with alternating settings and activities each week (Week A and Week B). Each session was 45 minutes in length and music was played intermittently throughout the session. The purpose of the program was to form intergenerational relationships, using music as a catalyst for these connections. During Week A visits, undergraduate university students led music engagement activities at LTC homes and elementary schools separately. During Week A at the LTC homes, university students would engage in music with the older adults that was familiar to them and promoted reminiscence. For example, popular Elvis Presley songs were used, as they were familiar to LTC and retirement residents who have lived in a Canadian context for

most of their lives. Depending on music exposure, the university students would play live music on ukuleles, pianos, and guitars, or pre-recorded music would be used to sing along to with the residents. When appropriate, the residents were also encouraged to use percussion instruments. There was also time for sharing and talking with the group. The music selections were driven by the purpose of forming intergenerational relationships, and varied between groups, as it was the university students' responsibility to select the music.

In the elementary school classroom component of Week A, the university students focused on relationship building through "senior sensitivity" training where they taught the elementary school students about pro-social behaviors (e.g., introducing themselves, shaking hands, etc.) while also encouraging them to critically think about what it would be like to live like a senior to promote empathy [5]. They also worked on ukulele skill building through rhythm games, practicing songs the students were learning on their ukuleles in class, and learning new songs on their ukuleles to share with the LTC residents (e.g., Skip To My Lou).

Week B visits consisted of combined visits in which the elementary school students and residents gathered at the LTC home and participated in facilitated activities. Some of the activities included singing songs and playing musical instruments together while also engaging in social activities that encouraged all participants to share and form deeper connections. The music was selected to promote connections between generations and consisted of the music the students were learning in class and music that both generations would be familiar with. The program concluded with the song "You are my Sunshine" performed by the students on ukuleles while the LTC residents helped the students through the song by holding the sheet music and singing along with them [5].

#### Outcome Measures

- 1. The Cornell Scale for Depression in Dementia is a 19-item clinician-administered screening tool for major depressive disorder that is validated for use with older adults living with dementia and LTC settings [6]. This scale involves two semi-structured interviews: one with a nursing staff member or social worker and one with the resident. Each item is rated from 0-2 to determine the summed score. The scale has high internal consistency (coefficient alpha: 0.84) and interrater reliability (kw = 0.67).
- 2. The Friendship Scale is a Likert scale self-assessment tool that contains 6 items that measures perceived social isolation [7]. The scale has high internal consistency, reliability (Cronbach alpha: 0.81), discrimination, and has been validated in the LTC resident population [7].

3. The Resident Assessment Instrument - Minimum Data Set (RAI) is a standardized measurement tool that evaluates each residents' strengths, needs, and risks to be detected, which then informs individualized care planning and monitoring. Data are collected at admission, then quarterly, and at discharge. Four sub-scales were used: behaviour, cognition, depression, and the index of social engagement [8].

#### Statistical Analysis

The statistical program R (version 3.5.1, Lucent Technologies) was used to compare pre- and post-intervention data points for all outcome measures. Repeated measures t-tests with significance threshold of p=0.05 were used.

#### Qualitative Analysis

Interviews contextualized and informed the quantitative data collected in the study. Qualitative interviews were conducted with five residents who participated in the program. The discussions with the older adults were facilitated by research assistants. Interviewees were asked open-ended questions about their interest in music, experiences in the FUP, and feedback for the future. Interview recordings were analyzed using generic thematic analysis. The qualitative research team consisted of four members: 2 research assistants trained in qualitative analysis who have experience facilitating the FUP (JS and BR); a recreation therapist experienced in program delivery (BH); and the lead researcher who is knowledgeable and experienced in music and health literature and FUP program delivery (CM).

#### Results

#### **Quantitative Results**

A total of 23 residents (female, 16/23, 69.6%; male, 7/23, 30.4%) participated in the study, 16 remained after participant dropout. The mean age was 88 and 76 for females and males, respectively. Overall significant declines were found in the Hawthorne Friendship and Cornell Depression Scales. Male Hawthorne Friendship score differences were found to be significant (t=-2.62,p=0.025), indicating higher feelings of isolation post-intervention. Furthermore, no significant differences were found in female Hawthorne Friendship scores (not shown in table 1). No statistical significance was found for all RAI outcomes between pre- and post-intervention periods. Additionally, statistical significance was not found between genders for all RAI outcomes and Cornell Depression scores. The statistical analyses for pre- and post- scores can be found in Table 1.

**Table 1**: Pre-intervention and Post-intervention measures

	Mean (SD)	T Scor e	Significance (Two-tailed)
Resident Assessment Index			
Pre RAI Behaviour	0.39 (0.722)	-1.21	0.234
Post RAI Behaviour	0.69 (0.793)		
Pre RAI Cognition	2.7 (1.43)	0.242	0.810
Post RAI Cognition	2.8 (1.56)		
Pre RAI Depression	1.4 (1.37)	0.204	0.840
Post RAI Depression	1.5 (1.97)		
Pre Social Engagement Score	4.7 (1.34)	0.682	0.500
Post Social Engagement Score	4.3 (1.78)		
Hawthorne Friendship Scale			
Pre Hawthorne	17.7 (3.45)	0.234	0.025
Post Hawthorne	14.3 (5.54)		
Cornell Depression Scale			
Pre Cornell	4.7 (2.95)	- 2.992	<0.01
Post Cornell	8.7 (4.67)		

#### **Qualitative** Results

Themes

Interviewed residents expressed decreased social isolation and a sense of joy and comfort when interacting with the elementary-school students. One resident during an activity "... befriended [a student]. You should see the beautiful card he made me." Engaging in music with the children also brought back many fond memories for the residents: "Music's always been in my life. I didn't start learning to play the piano until I was in my forties ... [if] you come down to my room right now, I could play continuously." Interview responses were positive overall, indicating increased cognitive activity and engagement. Programming also promoted socially-appropriate behaviours; one resident could "see how many [residents] were sitting around, who usually hardly moved at all, keeping beat." Another older adult found "[one resident] was actually singing [even though] he doesn't usually sing. He'll say, 'how are you today?', and then tries to [engage] and make another sentence and he just stops." Themes and corresponding supporting quotes can be found in Table 2.

**Table 2:** Themes from Qualitative Interviews from LTC Residents

Representative Quotes

Themes	Representative Quotes
Children bring joy	"I befriended [a child participating in FUP]. You should see the beautiful card he made me. It was really beautiful, and no mistakes."
Intergeneration al interactions strengthen over time	"First, they were kind of scared and shy, but not the last oneafter they got to know us, then they came right away to you."
Children improve my life	"You could see how many people were sitting around, who usually hardly move at all, [engaging] and keeping beat."
Music promotes a space to share experiences	"When I was 11, my dad wanted me to play the organ, so my dad put it in the paper for the fun of it for exchange for a bike, because it was more, and someone came who had a store with organs, and he came and fixed it up a little bit. It was probably second hand, but he made it that it was nice, and I learned to play organ on it. I played songs and church songs."

Promoting socially-appropriate behaviours	"Some of the residents on our floor are fairly non-responsive, they're in wheelchairs and they are just like this all day. Brian was actually singing, and he doesn't usually sing. He'll say "how are you today?", and then he tries to make another sentence and he just stops. But he was singing along there."
Feedback for future programming	"You might want to try a theme day. Like Beatles songs, so you wear something appropriate to that era."

#### Discussion

This intergenerational music program did not significantly decrease isolation or loneliness in older adults, nor did it significantly increase cognitive activity according to the quantitative measures utilized. Quantitative analysis revealed an unexpected significant increase in isolation and depressive symptoms for male participants, and non-significant increases among females between pre- and post-time periods. The study design for this intergenerational music program consisted of 12 weeks of consecutive programming, which may not be a sufficient amount of time to induce changes in these outcomes, as measured by the quantitative tools employed in this study.

Another intergenerational programming study utilizing music therapy observed similar results for their 10-week program, attributing their lack of significant increase of psychosocial benefits to logistical barriers and program length [9]. On the other hand, the findings of increased isolation and negative decline in cognitive ability over the course of the study period may be indicative of the inherent aging process and associated decline in mental and physical health that occurs in the LTC context. Furthermore, individuals entering LTC have increasing complex healthcare needs, causing their functional status to decline [10]. Thus, a longer intervention period, combined with higher program frequency, may be necessary to further evaluate the impact of this intervention.

Differences in RAI scores were not statistically significant, which may be attributed to the mixed and inconclusive pooled evidence of its psychometric validity reported by Hutchison and colleagues [11]. Moderate to strong psychometric validity was reported in studies conducted in research-controlled environments. RAI-MDS psychometric assessment in observational studies were found to contain risk of bias due to under-reporting and over-reporting of specific RAI-MDS questionnaire items. Finally, the cognitive status of participating residents was 2.7 prior to the FUP intervention,

which is indicative of participants having moderate cognitive impairment. This may have played a role in the non-significance of quantitative outcomes in this study.

Overall themes from the qualitative interviews were positive and aligned with the study objectives. Qualitative findings indicated an increase in cognitive activity and engagement among participants and promoted socially-appropriate behaviours. Participants found that the children from the FUP brought joy and improvement to their mental well-being. Other themes of LTC residents being able to share their experiences and reminisce with children were also present. These experiences were also reported in another qualitative intergenerational study using music therapy [12], where residents expressed how intergenerational interactions with children reminded them that there was a world beyond the LTC environment.

LTC residents who participated in the FUP intervention also experienced an increase in quality intergenerational interactions over time, demonstrating that new relationships between these populations may be uncomfortable at first, but that they require time to manifest into quality and meaningful experiences. This may help to increase empathy, understanding, and appreciation among both groups. Utilizing music in this intergenerational context also enabled the promotion of socially-appropriate behaviours, meaning music can facilitate integrative behaviour among older adults, as evidenced by residents participating and singing along during programming. The results of the qualitative interviews will inform changes that need to be considered in future program delivery. They will also provide important information about the needs of the residents at the LTC home and the impact of the FUP.

Limitations were encountered during the study process that have the potential to impact the reported findings. The research assistants (see Acknowledgements) for pre- and post-intervention data collection were different due to logistical challenges which may have introduced skewed results between raters. A small sample size was also analyzed; 23 participants were enrolled and by the end of the study period, 16 participants remained. Enhanced coordination between the study personnel and LTC staff to promote sustained LTC resident participation is vital. This could take the form of utilizing FUP volunteers to escort the residents to the program room to strengthen attendance. These factors make it difficult to generalize the quantitative findings of this study.

## Conclusion

The qualitative outputs of this study suggest that intergenerational music programming, such as the FUP, has

the ability to create meaningful relationships and decrease feelings of isolation. Future research should consider using alternative outcome measures, increasing the length of program duration, and utilizing stronger coordination between program coordinators and LTC staff

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Full-Length Article

# Care, compassion, & controversy: Supporting children in a Covid-19 vaccine pod through music therapy & child life

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#### Abstract

The Covid-19 pandemic has had a trajectory punctuated by controversy, from understanding the virus itself to the development of therapeutics and a vaccine. The offering of vaccination to children through a destination Covid-19 vaccine pod foregrounded the need for procedural support within a psychosocial reality of children and families navigating the pandemic. Children receiving the Covid-19 vaccine benefitted from an integrative approach synthesizing music therapy and child life services into interdisciplinary, and at times transdisciplinary care delivery that proved essential for not only the child, but for personal caregivers, and very often the nursing staff administering the vaccine itself. This article presents the praxis of psychoeducational interventions, psychotherapeutic support, and procedural support including both pre- and post-procedural interventions to support children receiving the Covid-19 vaccine,

Keywords: music therapy; child life; Covid-19 vaccine; procedural support

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#### Introduction

March 10, 2022, two years from the onset of the first Covid-19 lockdown, the pediatric Covid-19 vaccine pod at Mount Sinai Beth Israel (MSBI) victoriously marked its completed mission: the successful rollout of vaccines to over 900 New York City children in just four months. This brief period stands as an astonishing testament to the unique zeitgeist born of political tension and public skepticism about the pandemic, the development and approval of a vaccine, and the hospital's rich history in pediatric care. Pediatric care at MSBI has been steeped in a family-centered philosophy valuing the psychosocial care of children informed by the integration of music therapy and child life services. This article lends scope to the circumstances that were unique to this pediatric Covid-19 vaccine pod, and its offering to a community divided by ambivalence.

From the onset of the pandemic, its effect on pediatric populations has been one of discernable ambiguity. Vulnerability of the elderly and the chronically ill, warranting

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primary consideration naturally precluded pediatric patients, but the indiscriminate reach of Covid-19 told another story.[1,2,3] Understanding the far-reaching impact of Covid-19 to the young was of increasing importance in the quest to better understand the etiology of the virus, its spread and imminent mutations, and the vaccine rollout. [4-9] As the vaccine was made available to children and adolescents, scrutiny and mistrust, residual from the initial deployment of the vaccine was seen.

The breadth of literature on both procedural and surgical support spans age and diagnosis; from the use of music therapy to address pain,[10-17] to specific procedures ubiquitous to medical contexts. [18-27] Venipuncture with which anxiety and needle-phobia prevail [28-38] held poignance in the Covid-19 vaccine pod. Buttressed with literature on child life in the psychosocial care of hospitalized children, [39] this body of research renders a convincing case for the presence of one or both disciplines in a vaccination pod. While effective individually, the synthesis of the two professions raises the potential for optimizing the therapeutic outcomes in general and specialized pediatric settings. [23,24,39-42] But what is markedly striking about a destination vaccine pod, is that at no other time in recent history has the state of public health demanded a specific accommodation that such a pod could offer more than during this pandemic. Notably, the American Music Therapy Association developed a special Covid-19 task force to raise attention to the need and opportunity to serve children receiving the vaccine. [31] Despite the variance in public opinion, hordes of children brought to the vaccine pod by parents who were vaccinated themselves, reflected the increasing sentiment that the vaccine was safe, necessary, and the right thing to do.

The ubiquity of vaccine updates and age specific qualifiers across the media rendered an open-ended delivery of psychoeducation about the benefits, challenges, and ethical landscape surrounding the roll-out. [4-9] The provision of the vaccine to children once approved, resulted in several layers of need that were meetable and treatable through the integration of music therapy and child life in vacillation between interdisciplinary and transdisciplinary care delivery.

# Music Therapy and Child Life Integration in the Service of a Covid-19 Vaccine Pod

The first author began training board-certified music therapists seeking dual certification in child life in 2008, following his tenure at a well-known medical center in the New York tri-state area.[24,39,40,42] Dual certification proved to be a natural synthesis of the tenets of music therapy within a context of child life philosophy valuing the inclusive role of the child and the over-arching family system. Imparting the potential of this integrated approach at a fundamental level required a deconstruction of the most basic areas of needs assessment: what is the child's developmental understanding? how is the child coping?, and how is the child expressing and engaging in the environment? The interventions to address each area respectively are psychoeducation, procedural support, and psychotherapeutic support. Each area of focused intervention is aimed at supporting a child's mastery of illness, treatment, and context. This Music Therapy/Child Life Training Tool is included as an Appendix to introduce the mechanism that became an ongoing source of supervision and training during the second author's internship, which had aligned with the Covid-19 vaccine pod's trajectory.

In the case of children receiving the covid vaccine, this comprehensive approach to needs assessment was essential. For example, the clinician was able to assess a child's presentation upon arrival, noting signals of anxiety such as hypervigilance to proximity to caregiver, rapid social referencing across staff members, widened eyes, grimacing, and/or overt expression of worry. Observation of a child's engagement with the environment provided additional insight into possible coping strategies that could be utilized when the vaccine was being administered. Based on the assessment, appropriate procedural support could be provided seamlessly within an interdisciplinary culture of family centered care. This level of assessment was not only implicated for the child, but also for personal caregivers, and very often the nursing staff

administering the vaccine itself. For the latter group, efficiency, and time constraints especially during heavily scheduled windows could at times exacerbate anxiety for everyone. The praxis of psychoeducational interventions, psychotherapeutic support, and procedural support including both pre- and post-procedural interventions follows.

#### Caring for Children

The role of administering procedural support during the vaccination process proved vital from both music therapy and child life perspectives. The literature has supported the use of several techniques to provide re-engagement, re-direction, and reinforcement during procedures typically done in medical settings, including pediatric venipuncture. In a world where mass-vaccination came into play however, there were suddenly added stressors that affected the child, parent, and the healthcare staff. This included the concern about the psychological welfare of children undergoing the vaccinations. [39,47] In a politically charged environment, a child's potential exposure to "horror stories" at school and in the community was immanent given the highly publicized nature of the vaccine. Further compounding the emotionally charged environment was the pure stress of administering vaccines back-to-back with as many as 60 children within a 3-hour timespan. Several techniques proved efficacious in promoting a comfortable and safe environment to offset these factors.

Re-engagement, the act of therapeutically engaging the brain in a manner alternative to the primary stimulus, has proven to be an effective strategy in procedural support. A child life specialist often utilizes techniques that focus on tactile and visual re-engagement by introducing an alternative stimulus into the child's sensory field. In the Covid-19 vaccine pod, reengagement using vibro-tactile stimulation on extremities was offered to children prior to the procedure using a device in the shape of a ladybug that could be either held or attached to the child's arm. Often, the vibrating device would be placed directly below the venipuncture site. This would lessen the sensation of the puncture itself by refocusing the child to the alternative stimulation being offered. [47]

Music therapy practiced with a therapeutic focus on inclusion of the child and family in a process valuing authenticity, accurate language, agency, control, engagement, and feedback from the child contributed to the culture of the Covid-19 vaccine pod. [23,39, 47-50] Music therapy can provide additional methods of re-engagement through auditory stimulation that is individualized to each child's needs. Environmental music therapy (EMT) was utilized to neutralize the perceived sterility of a vaccine pod through the provision of music that was improvised to meet and modulate the sound environment to desirable levels.[46] A common technique utilized within the Covid-19 vaccine pod outside of

EMT, was the engagement of the child and family system through music entrainment. The entrainment, or matching, to the level of the energy being exhibited by the child in addition to physiological factors including respiration and movement with tension/release, promoted relaxation and grounding for the duration of the experience. [23.24,44,48,49]

Interdisciplinary support rendered through collaboration of music therapy and child life ensued from the professions' shared value of autonomy through choice-making. The child's choice of interventions across both child life and music therapy offerings, provided children with a sense of control during stress-inducing environments. Appropriate choices offered throughout the process included what color band-aid could be provided, what arm the vaccination would be administered to, and which method of re-engagement would be most effective for and preferred by the child. Providing autonomy whenever possible served to de-emphasize those instances when choice was contraindicated due to safety concerns such as excessive movement or combativeness.

Regardless of the clinician present at the time of vaccination, and certainly with transdisciplinary care, a fundamental step in supporting a child through the venipuncture process was consistent and repetitive positive reinforcement. Reinforcing each step of the vaccination process, allowed space for reflection on successes while also reorienting the child to the here-and-now in a non-threatening manner despite the potential anxiety they were experiencing. Positive reinforcement was most often provided through verbal praise, and reflection on past successes. This approach was especially impactful to children returning for their second dose.

Finally, once the vaccine had been administered, an additional "prize" would be offered by both nursing staff and the supporting clinician. This ritual served to ground and reorient the child back to present and provided an additional means of autonomy reinforcement through the choice of color or type of small prize. Simultaneously provided a necessary and positive interaction between the child and the administering nurse. The over-arching goal was to promote a sense of mastery in the child and to reflect back each positive coping strategy, behavioral response, and success that was observed during the vaccination process. Psychoeducational review of the successful strategies gleaned from the Covid-19 vaccine pod experience could potentially ensure better coping with venipuncture procedures in the future.

Following the procedure, appropriate steps were taken to support reconstitution [23,42,48,49] and a return to the child's baseline while promote a positive experience from beginning to end. To this end, a consistent practice included a "parade" of nurses, music therapy, and child life to celebrate their bravery and mastery during the vaccination process.

#### Caring for Families

The parent or caregiver can often be integrated into the care of the child to promote safety, security, and assistance during a potential fear-inducing procedure. Although there were occasional circumstances where assessment of a caregiver revealed discomfort or a diminished capacity to support the child throughout the experience, such instances rendered invaluable opportunities to provide both support and education. More often than not, the caregiver was highlighted as a comfort-figure and supportive presence to the child. Positioning for optimal comfort became a point of education as they were encouraged to provide a "bear hug" with the child placed on their lap. This position of comfort provided containment to promote increased physical safety for the child and staff in addition to increased emotional safety. [19,23,24,39]

Additionally, providing supportive presence and validation to the parent/caregiver was inherent in the process of vaccination. Expectedly, caregivers presented on a spectrum of emotional availability, expressivity, and understanding, which was assessed on an individual basis. One of the most effective and important aspects of supporting children is to further assess and support the caregiver to provide them with the tools that best meet both their needs and those of their child. Psychoeducation focused on the best practice for providing emotional support to the child through developmentally appropriate language, providing positive reinforcement in response to completed tasks, and physical support through positions of comfort such as the aforementioned "bear hug" technique.

In the Covid-19 vaccine pod, one of the most foundational tenets of psychoeducation with caregivers was the consistent introduction and reinforcement of accurate and fitting language that would affirm the process, validate the child, and provide a foundation of trust and safety for the child. Modeling an effective communication style in the hospital can potentially transfer to better communicating at home. The most frequent inaccuracy presented by caregivers was the phrase "it won't hurt". Introducing the expectation of a painless experience, provides a false sense of security that when disproved, creates an inherent mistrust of the caregiver that could impact other situations for the child. Rather than negating or denying the possibility of pain, caregivers were encouraged to instead listen, validate, and respond. If the child displayed fear, it was encouraged and modeled by the clinician to have a dialogue about the fear itself rather than introducing any potential causes or contributors to the feeling. If a child indicated fear of the vaccine, the focus then moved to validating that fear and finding a method of coping and re-engagement that could be either facilitated by the clinician or caregiver. Often, there would be a dialogue where the caregiver or child could identify

previous successes and positive outcomes of other fear-related memories.

#### Caring for Staff

For many, the Covid-19 vaccine pod raised awareness of dynamics driven by power, privilege, culture, and certainly those specific to family systems already under the stress of the pandemic. Given the history of how the pandemic and vaccine development had been managed in the United States, such dynamics were anticipated. In addition, however, there emerged an unlikely area of need expressed by nursing and medical staff attending to the Covid-19 vaccination pod either by voluntary choice or by reassignment. Caring-for-thecaregiver techniques long-practiced within the Louis Armstrong Department of Music Therapy of the Mount Sinai Health System, has driven the on-going recognition and meeting of staff needs as they have arisen.[52-54] Mentoring and modeling developmentally focused care as it unfolded in real time, and decompressing through retrospection as part of the pod's closing ritual each day, became consistent features of the integrative care that was provided.

#### Conclusion

Music therapy and child life integration as a conduit for procedural support proved to be both effective and efficient at meeting the needs of children receiving their Covid-19 vaccine. Interdisciplinary collaboration, and the potential for transdisciplinary care to occur when possuble ensured a consistent delivery of quality care. The integration of psychoeducation with psychotherapeutic goals through a range of expressive opportunities was an individualized approach made possible when traditional siloed thinking was transcended. For children and families negotiating social stigma and ambivalence about the Covid-19 vaccine, there was an inherent need for support and validation that they were in the right place. Integrative philosophy ensured that individualized support immediately upon arrival to the Covod-19 vaccine pod could be sustained through the entire experience of receiving the vaccine.

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Appendix

# MUSIC THERAPY/CHILD LIFE TRAINING TOOL © John Mondanaro 2008

AREA OF ASSESSMENT	CLNICAL INTERVENTION
Patient's understanding of illness	Psychoeducation/Medical Play
Developmentally on track  Delayed	Begin with what child does know  Explain sequence of events
Regressed	Explain sensory aspects
Prior experience  Demonstrates mastery	Demonstration of procedure on dolls/manipulatives
Patient Coping	Procedural Support
Compliant or non-compliant	Visual engagement (art, crafts, videos)
Combative	Auditory engagement (music engagement, entrainment, soundscape)
Passive or active  Engaged or withdrawn	Tactile engagement (drumming, strumming, vibration)
	Olfactory (aroma therapy)
	Taste (flavored lip balm, snacks of permissible)
Patient Expression of Feelings	Psychotherapeutic Support
Demonstrates relatedness  Articulates self-narrative	Assess for themes of loss, separation, isolation, change, transition, betrayal, self-blame
Engages with staff  Asks questions	Facilitate forums for verbal and nonverbal expression (art, music, expressive play, etc.)
Identifies and asserts needs	Identity affirmation

Full-Length Article

# Perspectives on dementia from a speech-language pathologist: An interdisciplinary focus Linda Carozza<sup>1,2</sup>

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#### Abstract

Considerations of current and future aging demographics necessitate understanding of assessment approaches to ensure that projected public health needs are met accordingly. Status of medical conditions, available technologies and supports are described to underscore the critical need for planning and instituting provisions supporting assessment strategies to meet the broad global needs of developing countries. Assessment administration and considerations are presented. Greater emphasis on the details of assessing may lead toward creative expansion and a broadening of treatment options. This article describes current and future needs for assessment of dementia using a world view approach.

Keywords: Dementia assessment, adaptations, creative approaches, global viewpoint

Multilingual abstract | mmd.iammonline.com

#### Introduction

Collaboration amongst allied professionals providing support to the vulnerable and ever-expanding population of individuals with dementia and its variants is growing. Increasingly, we find individuals with dementia being supported and sustained in community group programs, including those specialized in implementing creative arts therapies. The impact of early detection in building resilience can help to stabilize the progression of dementia. This may be of tremendous importance as engagement in creative arts therapies seemingly helps to build resilience amongst the insidious decline that accompanies this disease. Music therapy professionals have taken a leadership position in this arena and have contributed significant analyses to the assessment of dementia.

Dementia is one of the most significant causes of late-life decline in the United States and worldwide. With the explosion of the aging demographic, the incidence of this disorder stands to increase exponentially in the coming decades, with no known cure yet identified. As published by the World Health Organization, [1] the worldwide population of people over the age of 60 is exponentially increasing, and the number of individuals in this demographic will have doubled to 2 billion between 2000 and 2050. What may not be well-known, is the fact that in addition to US demographics, a large portion of this population exists in the Western Pacific Region and are identified by WHO, as one of the fastest growing regions of people 65 and over in the world. The over 200 million people

PRODUCTION NOTES: Address correspondence to: Linda Carozza, E-mail: <a href="mailto:lcarozza@pace.edu">lcarozza@pace.edu</a> | COI statement: The author declared that no financial support was given for the writing of this article. The author has no conflict of interest to declare. already in this area will likely double by 2050. Furthermore, the World Health Organization European Region, represents another rapidly growing aging demographic, with the highest median age in the world, and people aged 65 and over are expected to increase from 14% in 2010 to 25% in 2050. These statistics are a product of a longer lifespan and better health and wellbeing in these areas. This results in the need to understand and plan for health needs of the elderly, as a worldwide imperative.

As a speech-language pathologist specializing in dementia assessment, these statistics and an expanding world view inform my practice in treating people in the US and from other countries who have emigrated to the US. However, estimates of occurrences remain elusive due to a number of constraints affecting population statistics. Most significant, is the fact that there is a lack of consensus on diagnostic terminology and staging descriptors in dementia which in turn affects the precision of subject matching, resulting in a lack of reliable population projections.

As diagnosis in the incidence and prevalence of dementia subtypes depends on analysis of communication decline, there is an urgent need to increase understanding of communication (speech, language, and cognitive functions) as these areas are primary and necessary areas for diagnosing the presence of dementia. Establishing the speech and language comorbidities of dementia subtypes provides critical information for speech-language clinicians to share with neurologists, primary practice physicians, psychologists, social workers, creative arts therapists, and all treatment team members to best inform families about the presence/absence of dementia and care planning.

#### **Describing Dementia**

Dementia is a broad diagnostic umbrella with distinct established subtypes. Considering the rapid advance of available imaging and laboratory studies that are anticipated to be developed in the near future, it seems likely that related diagnostic interventions will become increasingly essential in the future. Alzheimer's Disease is a major subtype of dementia consisting of characteristic plaques and tangles seen at the time of post-morbid brain autopsy.[2-3] It is, however, relevant to note that autopsy reports of brains with these characteristic pathologies may or may not yield consistent clinical behavioral correlations. Therefore, it is the role of professionals such as speech-language pathologists to evaluate patterns of communication decline that contribute to the projected medical diagnoses and planning. This holistic view of dementia assessment assists global healthcare communities in uncovering early onset as we work toward developing care programs that ensure best quality of life for individuals and their family partners. Furthermore, related strategies can be developed and modified for individuals both in the US and particularly where there are probable limited resources in health care and technology. This in turn is affected by disparities resulting in varying levels of diagnostic accuracy. The influence of socio-cultural attitudes, for instance, reflect major differences in health care capacity and this ultimately influences capacity for longevity and quality of life.

Dementia is also detected by the absence or presence of related comorbidities, such as sensory changes, visual perceptual disorder, and dysphagia, to highlight a few. Based on these complexities, it is clear that there is an urgent need for increased data regarding differential diagnoses. Currently, there are a plethora of underlying diseases that fall under the term dementia. These include frontal temporal lobe disease, cortico-bulbar deterioration, and many others. Estimates of underlying diagnoses are on the rise and resources to meet the diagnostic demands stand to be rapidly outstripped given the projected increase in prevalence in the near future. Accordingly, The WHO has established a world dementia plan.4 The plan marks an effort to analyze and anticipate the needs of dementia sufferers throughout the world, and includes regions such as Africa, the Americas, Southeast Asia, Europe, Eastern Mediterranean and the Western Pacific in an effort to share and expand dementia care for all.

#### Burden of Care

Sleeman and colleagues[5] implemented the Lancet Commission on Palliative Care and Pain Relief and WHO mortality reports (2016–60)[4] that provided compelling inforrmation projecting the social, medical, economic, and

human cost that can emanate from serious life-limiting illnesses such as dementia. Their report advocates for the investigation of how this burden of care may serve to inform health system policy. Their analysis projected worldwide burden of serious health-related issues through 2060 and warned of its impact on world region, age groups, and overall health conditions.

In predicting estimates for 20 serious medical conditions typically leading to the need for palliative care they concluded that:

By 2060, an estimated 48 million people (47% of all deaths globally) will die with serious health-related suffering, which represents an 87% increase from 26 million people in 2016. 83% of these deaths will occur in low-income and middle-income countries. Serious health-related suffering will increase in all regions, with the largest proportional rise in low-income countries (155% increase between 2016 and 2060). Globally, serious health-related suffering will increase most rapidly among people aged 70 years or older (183% increase between 2016 and 2060). In absolute terms, it will be driven by rises in cancer deaths (16 million people, 109% increase between 2016 and 2060). The condition with the highest proportional increase in serious-related suffering will be dementia (6 million people, 264% increase between 2016 and 2060.[4]

This analysis highlights the burden of serious illnesses on subsequent local, national, and international communities and a need for resource development. They reflect on the greatest increases occurring in low-income populations, and older people, with increasing dementia diagnoses almost doubling in numbers. The authors projected that the highest proportional increase in dementia would result in 6 million new cases, a massive 254% increase between 2016-2020, representing a near-doubling of burden of care to individuals and society at large. This is catastrophic since many countries have no system of palliative care for dementia survivors (approximately 45% are without palliative care resources according to the authors). In the US and elsewhere, long term care poses a huge financial and social burden, with in-home and institutional care both steadily becoming extremely limited. Understanding the 'big picture' of dementia-related issues, including the lack of definitive diagnosing, no medical cure, and a lack of standardof-care combined, all serve to endanger an already weak system of resources for the most vulnerable members of society.

#### Challenges

It bears critical mention at this point that older definitions of dementia which were chiefly characterized by a pen and paper assessment of impairment in memory, language, thinking, and/or daily living abilities, tended to be more generic in the recent past. However, with access to advanced medical technology, there is a growing differential diagnostic capacity to analyze many disorders earlier on in the disease process. Features of the symptoms may share the general diagnostic label of 'dementia' as a disease of progressive neuropathological decline in brain structure and function, yet can show different patterns of presentation and disease course. The neurocognitive features of dementia which comprise the most salient diagnostic characteristics are: substantial cognitive decline from a previous level of performance and cognitive deficits in complex attention, executive ability, learning,

memory, language, perceptual-motor-visual perception praxis, and social cognition. These serve to interfere with independence in daily living and are not related to delirium and cannot be attributed to another mental disorder.[6]

The classification and staging of neurocognition is essential for appropriate early referral and care, especially when the cause of apparent dementia may be due to reversible features resembling dementia, such as depression, polypharmacy, and nutrition to name a few. Suspicion of dementia, also known as unspecified dementia, can be difficult to confirm through differential diagnosis. The clinical features of the major dementing illnesses can be found in Table 1.

**Table 1:** Clinical Features of the Major Dementing Illnesses

	Cognition	Memory	Language	Behavior	Motor
Alzheimer's	Poor safety awareness, impaired executive function, disorientation	Frequent forgetfulness, repetitive questions, impaired episodic memory	Impaired word retrieval, communication abilities decline, reading is preserved in early and middle stages	Depressions, paranoia, withdrawal, mood changes	Difficulty performing simple tasks
Fronto-temporal Dementia	Impaired executive function, decreased inhibition, impulsivity	Can be impaired, but not the primary feature	Impaired word retrieval, conversation, and comprehension deficits	Wide range of behavioral changes, especially frontal lobe variant, uninhibited behavior, including inappropriate social behavior	Tremor, rigidity, swallowing difficulty, weakness
Lewy Body	Impaired attention, concentration, executive function, difficulty completing complex tasks	May not be impaired in early stages	Intact in early stages	Depression, lethargy	Rigid and stiff muscles slowed movements
Vascular Dementia	Impaired executive function	Progressive loss of memory and attention	Dysarthria, less spontaneous communication	Various behavior changes	Slowness, poor balance, unsteady gait
Mild Cognitive Impairment	Can be generally intact	Frequent forgetfulness of recent information	Mild word retrieval, forgetfulness of train of thought	Depression, anxiety, increased irritability	
Mixed Dementia	May be variably affected with significant findings	Tends to be variably affected with significant findings	Impaired word retrieval	Increased anxiety, depression and paranoia. Changes in the individual's personality	Limited control of body movements

Communication disorder is an established characteristic in diagnosising dementia. The pathology of dementia and specific particular sub-types center on the loss of purposeful communication as well as a loss of lexical activation networks. In fact, a change in word-finding ability is one of the main complaints that brings a family into a provider's office for assessment.

Other prominent changes include inevitable physical and cognitive declines. The World Health Organization acknowledges that this encompasses deterioration of cognitively related abstract language functions, such as comprehension and the use of metaphoric language, humor, sarcasm, and double-entendres which comprise mature dayto-day interpersonal communication. There is also the inevitable decline and ultimately loss of secondary language representation (i.e., reading, writing, math.) Word finding and problem-solving pragmatic domains are most notably diminished in the early stages, while structural elements such as basic grammar rules and rote language (i.e., counting, familiar songs) will generally be preserved until later disease progression. However, an inevitable decline of motor speech and vegetative function including articulation precision, prosodic tone, and coarticulation in rapid speech will follow. Ultimately, patients who survive to late stage may become mute and have central nervous system damage to feeding and swallowing skills. This downward deterioration is a hallmark of the disease and directly related to the central nervous system deterioration of the disease which contributes to final morbidity.7 The majority of patients will lose propositional meaningful novel language first, then may have preserved rote language functions for a period. Only highly rote social greetings and occasional music recall may remain but, unless integrated within a therapeutic plan, may not be useful for directive interaction-such as meaningful question and answer dialogue.

The speech, language, communication, and motor speech changes associated with the most prominent dementia subtypes are summarized in the Table 2. There may be prominent changes in oral motor control and coordination that follow as the disease progresses, with dysphagia being a common characteristic particularly as the disease advances and leads to an inability to chew and swallow. This may lead to decision-making about alternative methods for feeding and medicine administration such as intravenous apparatus; and/or other medical decision-making involving withdrawal of nutrition and end of life care. As speech and language are necessary diagnostic factors of dementia, a breakdown of speech-language changes by dementia subtype is provided in Table 2.

 Table 2: Speech and Language Changes by Dementia Subtype

Dementia Subtype	Speech and Language Changes			
Alzheimer's	Significant decline in semantics word-finding difficulties, as signaled by long latencies paraphasias, word substitutions difficulty with topic maintenance echolalia, lack of meaningfu speech, gradual progression to mutism			
Vascular Dementia	Word retrieval difficulties, difficulty following instructions, slurred speech, dysarthria, less spontaneous communication			
Lewy Body Dementia	Motor speech disorder with hypophonia, disorganized speech			
Frontotemporal Dementia	Progressive decrease in expressive vocabulary, word- finding			
	problems, reduced spontaneous conversation, echolalia and meaningless repetition of phrases			

American Speech-Language-Hearing Association. (n.d.) *Dementia* (Practice Portal) <a href="https://www.asha.org/practice-portal/clinical-topics/dementia/">https://www.asha.org/practice-portal/clinical-topics/dementia/</a>

The ensuing propositional communication loss in dementia relates directly to quality-of-life decline and the difficulties a patient can have in sustaining any form of independent living. Confabulations, decline/distortion of problem-solving abilities, hallucinations, and incoherence can render an affected individual unable to sustain even a supervised independent lifestyle. Such pathological declines co-occur with other changes in function such as distortion in reality orientation and even a lack of recognition of one's familiar surroundings. Therefore, many patients require supervision for their safety and well-being.

On varying scales, the burden to families is largely unsustainable, especially in households where adults are required to go out to work to support a family. The cost of inhome care is prohibitive to most families, and the availability of supervised day programs is relatively scarce as well. Taken on a national and international level, with elderly populations tending to live longer, there is an intolerable burden on most families' resources, economic and otherwise.

World-wide, the best available strategies include the earliest detection, careful differential diagnosis, and access to the latest medical interventions including potential experimental trials.

#### **Assessment Overview**

Early detection is one of the most important ways to alleviate the humane and societal costs of dementia care. The following is a brief overview of some of the best practices recommended in the current literature, though this review is not exhaustive. The assessment of patients via cognitive screenings versus providing full formal batteries can be an expeditious way to evaluate who may be at risk for dementia, and may serve to differentiate those who may have other conditions. The careful identification of dementia and its variants by means of clinical and instrumental efforts is a worldwide research endeavor that stands to increase the quality of life of millions of people and their loved ones currently and in the future.

In line with this, commonly used cognition screening tests include the Mini-Mental States Examination (MMSE),<sup>8</sup> the Mini-Cog Test,[9] the Montreal Cognitive Assessment Test for Dementia (MoCA),[10] The Addenbrooke's Cognitive Examination Revised (ACE-R),[11] and the General Practitioner Assessment of Cognition (GPCOG).[12] Each of

these tests is brief, typically under 30 minutes, and can assist in establishing cutoffs leading towrard further assessment.

Assessments of overall dementia severity include the Clinical Dementia Rating Scale (CDR),[15] the Global Deterioration Scale (GDS),[14] and the Clinician's Global Impression of Change Scale (CGI).<sup>15</sup> The GDS, developed by Dr. Barry Reisberg, [15] divides primary degenerative dementia into 7 stages. The contribution of staging is especially critical in dementia since strategies for patients and caregivers are specific to patient care needs at each level of decline. The first 3 stages range from no cognitive decline to mild cognitive decline. Stages 4 and 5 describe moderate and moderately severe decline. The final two stages, 6 and 7, describe severe cognitive decline and very severe cognitive decline, respectively. Stage 7 includes the loss of all verbal abilities, basic psychomotor skills, toileting, and feeding abilities. References from ASHA provide the material for the following information, including prognostic information. As indicated in Table 3.

Table 3: Assessments for Dementia

Assessment Tool	Description	Probability of accurate diagnosis
Montreal Cognitive Assessment (MoCA; Nasreddine, 1996)	The MoCA evaluates cognitive abilities, including orientation, short-term memory, executive function, language abilities, attention, and visual-spatial abilities.	Sensitivity of 100% in detecting mild Alzheimer's and 90% for detecting MCI (Nasreddine et al., 2005)
Mini-Mental State Exam (MMSE; Folstein et al., 1975)	The MMSE is a widely used test of cognitive function among the elderly. It includes tests of orientation, attention, memory, language, and visual-spatial skills.	Sensitivity of 85% in detecting dementia (Creavin et al., 2016)
Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi et al., 2006)	The ACE-R is a dementia screening test that incorporates five sub-domain scores: orientation/attention, memory, verbal fluency, language and visuospatial.	Reliability of the ACE-R is considered very good, alpha coefficient = 0.8 (Mioshi et al., 2006)
General Practitioner Assessment of Cognition (GPCOG; Brodaty et al., 2002)	The GPCOG is a screening tool for cognitive impairment consisting of seven stages.	Sensitivity and specificity of the GPCOG range from 0.81 to 0.98 and 0.72 and 0.95, respectively (Seeher & Brodaty, 2017)
Repeatable Battery for the Assessment of Neuropsychological (RBANS; Randolph, Tierney, Mohr & Chase, 1998)	The purpose of the RBANS is to determine the neuropsychological status of adults ages 20-89 with neurologic injury or disease, such as dementia.	Standardized on 540 adults selected to represent the U.S. population demographics

Assessment Tool	Description	Sensitivity & Specificity	Time to administer (minutes)	Cost
Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi et al., 2006)	The ACE-R is a dementia screening test that incorporates five sub-domain scores: orientation/attention, memory, verbal fluency, language and visuospatial.	Sensitivity of 0.90 and specificity of 0.93 (Mioshi et al., 2006)	15-20	No cost
General Practitioner Assessment of Cognition (GPCOG; Brodaty et al., 2002)	The GPCOG is a screening tool for cognitive impairment consisting of seven stages.	Sensitivity of 0.82 and specificity of 0.83 (Seeher & Brodaty, 2017)	6	No cost
Mini-Cog: Screening for Cognitive Impairment in Older Adults (Borson et al., 2003)	The Mini-Cog was constructed from 3-word recall, a common element in many cognitive screening tests and the earliest to decline impairment in common dementias such as Alzheimer's disease, and a clock drawing task included as an executive/cognitive composite.	Sensitivity of 0.76 and specificity of 0.89 (Borson et al., 2003)	3	No cost
Mini-Mental State Exam (MMSE; Folstein et al., 1975)	The MMSE is a widely used test of cognitive function among the elderly. It includes tests of orientation, attention, memory, language, and visual-spatial skills.	Sensitivity of 0.79 and specificity of 0.95 (Hancock and Larner, 2011)	5-10	MMSE-2: Expanded Version Kit (User's Manual, Blue and Red Forms, Scoring Templates, Pocket Norms Guide): \$259.00
Montreal Cognitive Assessment (MoCA; Nasreddine, 1996)	The MoCA evaluates cognitive abilities, including orientation, short-term memory, executive function, language abilities, attention, and visual-spatial abilities.	Sensitivity of 1.00 and specificity of 0.87 (Nasreddine et al., 2005)	10	MoCA test training and certification: \$125.00
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr & Chase, 1998)	The purpose of the RBANS is to determine the neuropsychological status of adults ages 20-89 with neurologic injury or disease, such as dementia.	Sensitivity of 0.98 and specificity of 0.82 (LaPointe & Homer, 1998)	20-30	RBANS Updated Combo Kit (Includes Stimulus Books, Coding Templates, and Manual): \$752.80
Six-item Cognitive Impairment Test (6CIT; Brooke & Bullock, 1999)	The 6CIT is a brief cognitive screening test containing three orientation items that is widely used in primary care settings.	Sensitivity of 0.90 and specificity of 1.00	3-4	No cost

## Ongoing assessment through the rapeutic interventions – An Overview

Contributions from the music therapy literature

An early important music therapy study by Lipe et al.[21] included 50 subjects, and compared the Mini-Mental State Examination (MMSE), the Residual Music Skills Test (RMST) and the Music-Based Evaluation of Cognitive Function (MBECF). Significant correlations were noted as well as additional information regarding the unique contributions of music cognition to general cognition.

The MMSE can predict MBECF performance and thus has predictive validity, which is important in the collaboration of inter-professional communities serving the dementia population. Proposed specialized neural networks may underlie performance that is maintained in certain test populations, which can be useful in diagnosis as well as in the development of treatment strategies. The authors pointed out that the patterns of the relationships between these instruments should be further examined for correlation properties particularly in verbal and rhythm performance, which can assess the contribution of task-dependent findings. The predictive abilities of music-based cognitive assessment is a valuable contribution in the arsenal of dementia assessment especially in considering that early detection is essential for appropriate referral and management.

In 2015, a Music in Dementia Assessment Scale (MIDAS)[24] was developed. A unique aspect of this measurement tool is its incorporation of information gathered from a focus group which contributed to its content validity. Field testing supported by qualitative metrics yielded consensus and experimental results that can be reliably used to assess individuals with dementia using music therapy-based protocols, as supported by valid measures of interest, response, initiation, involvement and enjoyment as meaningful outcome measures. The MIDAS is therefore an additional valid assessment instrument in dementia using music therapy as a diagnostic platform. It can be implemented by staff and music therapy professionals alike. These in-field reports are important in bringing as much diagnostic and planning information into the hands of the treating professionals as possible.

The effectiveness of music interventions for people living with dementia was tested during a cluster randomized controlled in Australian residential aged care facilities (RACF).[20] The study emphasized the detriment of delays in beginning the baseline assessments and intervention delivery due to the COVID-19 pandemic on the efficacy of music interventions. The study underscored the importance of focusing on building relationships with RACF staff and resident families and reducing the time between initial

assessments and intervention. Furthermore, the study revealed the difficult work conditions due to staff shortages, heavy work schedules, time constraints, and demands of the 'caring' role.

Concetta Tomaino, who currently serves as executive director and co-founder of the Institute for Music and Neurologic Function (IMNF), explains that for people with neurodegenerative diseases, such as Alzeimer's dementia, music can be "a window to their memories." The auditory system has networks throughout the brain that are aroused and stimulated by patterns of sound. Those patterns of sound can stimulate motor function and attention. Music interventions, including listening and responding to familiar songs, writing music, and other expressive and creative music-related activities, can be used to enhance quality of life by strengthening cognitive abilities, such as short-term memory and information pairing ability, as well as physical abilities (queuing of gait, balance, coordination, and confident movement).

It can be concluded that incorporating music in varying contexts of dementia care is widely practiced and its implementation is relevant and advantageous. In accommodating this area of practice in assessment protocols and looking toward integrative mechanisms of treatment, speech-language pathology, and music therapy collaborations may yield stronger diagnostic interprofessional practice guidelines and resources. Co-delivered programs in speech and language therapy along with music therapy has an established potential in acquired neurogenic populations with positive outcomes reported in collaborative studies.[25] Continued research and development in this area should be valued as a promising, highly viable and cost-effective assessment pathway.

While the primary emphasis of this article is the description, comparison and understanding of assessing dementia, prominent reported treatment paradigms in the current literature are critical to mention. This is especially important since public health factors call upon integrative communal strategic planning as the increase in cases requiring diagnoses has risen in need, which neccesitates the value of accurate assessment.

It follows therefore that since there is no known cure for dementia, the goal of alleviation of symptoms and prolonging quality of life is of critical importance world-wide. An abundant array of literature is aimed at patient and family care with varying degrees of scientific support. As a prominent example, in speech-language pathology, methodologies that might help a patient retain and recall salient information and important routines for daily functions have been increasingly identified with related research support. While at present, the evidence-based interventions remain scant, clinicians currently report a level of success with specific methodologies, namely spaced

retrieval strategies. [26] A further functional strategy has been in the area of environmental supports for this client population, such as 'memory' gardens, horticulture activities, the use of iPads to greet a loved one in the morning, therapeutic companions such as animal-assisted therapy, robotic pets for interaction, and other stimulating and creative individualized care. However, these interventions for both assessment and continued quality of care are out of reach of most families, who may be older themselves with no financial or travel access to centers providing innovative care.

Nevertheless, skilled clinicians can capitalize on the knowledge of personal routines for both assessment and quality of life in providing "low-tech" strategies. Some of these important techniques include assurances that patients feel secure through basic physical companionship. Meaningful eye contact, well-modulated vocal tones, familiar routines and reassurance are examples of simple strategies. These are in addition to monitoring changes in function accommodating, understanding the role of medications on arousal states, capitalizing on sustained procedural memory for routines, and addressing the client's social-emotional and cultural comfort levels through familiar activities routine activities that encourage patients' sense of safety and control. In all endeavors, person-centered approaches and related social daycare programs customized to familiar environments and personnel will yield the most reliable results for ongoing monitoring and care planning. These and other salient reports of quality of life, non-pharmacologic assessment and therapeutic considerations are outlined by Carozza.<sup>7</sup> In maximizing our understanding of published data and adapting clinical environments for individualized consideration, integral aspects of care, such as maintaining non-threatening environments, adhering to low arousal situations, and in imbuing person-centeredness, clinicians will find the greatest success in meaningful assessment and planning.

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Full-Length Article

## Neglect, virtual reality and music therapy: A clinical report Andrew Danso<sup>1,2</sup>, Mikaela Leandertz<sup>1,2</sup>, Esa Ala-Ruona<sup>1,2</sup> & Rebekah Rousi<sup>3</sup>

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### Abstract

Neglect is typically experienced after suffering from a stroke. Despite various rehabilitative interventions used in treatment for neglect, there is no consensus about the most effective intervention or treatment. Virtual Reality (VR) combined with music therapy practices may offer a promising intervention for use during neglect rehabilitation. This review summarises evidence of existing interventions and assessments used for post-stroke and neglect rehabilitation on patients in VR and music therapy research. Non-systematic searches of the PubMed and PsycINFO databases were conducted to retrieve relevant articles. Overall, literature found in small studies suggests promising findings for symptom reduction during neglect rehabilitation through the use of VR and Musical Neglect Training interventions. This was coupled with a demonstration of feasibility and safety. Novel evidence is found in stimulation of specific neurological regions in neglect patients during exposure to a VR intervention. However, larger trials with consistent assessments are needed to arrive at generalisations. Based on the evidence reviewed, the article explores intersections of VR and music therapy interventions with the purpose of neglect rehabilitation.

Keywords: Stroke; neglect; rehabilitation, music therapy, virtual reality

Multilingual abstract | mmd.iammonline.com

### Introduction

#### Focus of the Review

Despite various rehabilitative interventions used for treatment of neglect, there is no consensus about the most effective intervention or treatment [1]. Given the lack of research exploring the combined use of VR and auditory cues to neutralise neglect bias, a review identifying and describing interventions and assessment in VR and music therapy research applied to stroke and neglect populations would provide an understanding of whether or not such an intervention is applicable for treating neglect. Therefore, this review summarises evidence of existing interventions and assessments used for post-stroke and neglect populations in VR and music therapy research.

#### PRODUCTION NOTES:

Address correspondence to: Andrew Danso | Address: Centre of Excellence in Music, Mind, Body and Brain; Department of Music, Art & Culture Studies (MACS), PO Box 35 (M), FI-40014, University of Jyväskylä, Finland |E-mail: andrew.a.dansoadu@jyu.fi | COI statement: The authors declared that the work was supported by the Centre of Excellence program 2022 – 2029 of the Academy of Finland. The authors have no conflict of interest to declare.

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### The Neglect Syndrome

Neglect is a common result of a right hemispheric stroke in the brain. This affects approximately 60% to 70% of stroke populations. [2,3,4] State that neglect is caused due to damage to the multisensory cortex, where the auditory and visual input combine to construct spatial representations of our body's position in relation to our environment. Neglect may also be referred to as hemineglect, spatial neglect, visuospatial neglect, visual neglect, unilateral spatial neglect (USN), paresis, and hemiparesis. [5] indicate the frequency of patients suffering with neglect in the United States is estimated to be from 13% to 81% in populations who have experienced a right hemisphere stroke. They also describe rates in other countries that exist at approximately 50% of the stroke population.

## Areas of Functioning Affected by Neglect

Neglect can affect various areas of functioning. Often the functions affected include impaired neurological performance, motor performance of the limbs and perception. According to [6], the distinct deficit in patients experiencing neglect is an orientation bias to the right. There are two categories of neglect that affect functioning. These categories are: 1) how neglect affects behaviour (e.g., physical sensation, and motor

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movement) and 2) how much it disrupts perception (e.g., personal awareness or spatial awareness) [1,7,8,9]. In a recent review, neglect is described as causing comorbid visual conditions such as strabismus, greatly increasing the risk of a fall [10]. There is further evidence that patients suffering from neglect cannot accurately perceive time. This is known as time discrimination [11], which causes disruptions to visual attention when directing it over time [12]. Furthermore, neglect weakens the accuracy in perceiving sounds when audio tones are presented in the neglected area, e.g., the left ear [13,11,14]. Due to the combined auditory (perception of sounds) and visual (directing visual attention) impairment caused by neglect, these disabling effects can impede patient participation and adherence to rehabilitation programs. It may also decrease patient independence in activities of daily living (ADL). Furthermore, patients with neglect report higher scores for depression than non-neglect patients [15].

## Neglect Rehabilitation and Recovery

Following neglect, rehabilitation and recovery is needed by patients. Differences between rehabilitation and recovery are important to outline. [16] defines rehabilitation "as any aspect of stroke care that aims to reduce disability and promote participation in activities of daily living" (p. 239). [16] also describes rehabilitation as being a "process... to prevent deterioration of function, improve function, and achieve the highest possible level of independence" [16, p. 239]. Recovery associated with neglect is defined as "improvement across a variety of outcomes, beginning with biological and neurologic changes manifesting as improvement on performance and activity based behavioral measures" [16, p. 239].

Typical neglect rehabilitation is closely related to stroke practices, and may involve its associated interventions. These may be the following, but not limited to: a) Physical interventions, such as muscle strengthening, repetitive task training, constraint induced mobility therapy, mirror therapy, gait rehabilitation and botulinum toxin; b) Regenerative interventions, such as cognitive rehabilitation, non-invasive brain stimulation, neuromodulators and drugs to enhance motor recovery; c) Remote rehabilitation interventions, such as telerehabilitation, biotechnology and wearable sensors, and brain-computer interfaces; and d) Intervention technologies for rehabilitation such as robotic devices, VR and electrical stimulation [17].

## Neuroplastic Changes post-stroke and Musical Stimuli

A fundamental aspect of post-stroke and neglect rehabilitation is inducing neuroplasticity. Neuroplasticity is generally understood as the capability of the nervous system to respond

to intrinsic and extrinsic stimuli through reorganization of its structure, function and connections [18, 19]. Evidence for understanding neuroplasticity and the nature of how the brain functions when exposed to musical stimuli has been found through studies engaging in music, actively or passively, as well as the use of music-based interventions on various populations [20, 21]. The multisensory and multimodal actions of music engagement and music-making activate various neural pathways in the brain - this multi-modal aspect of music may be the reason for its role in supporting plastic changes in the nervous system [19]. Recently, music-based interventions have been used in the rehabilitation of traumatic brain injury [22] and stroke [23, 24].

## Neurological Music Therapeutic Approaches

In recent years, music therapy practices have been researched, developed and applied to stroke and neglect rehabilitation. [25] states that "music therapy is a systematic process of intervention wherein the therapist helps the client to promote health, using music experiences and the relationships that develop through them as dynamic forces of change (p. 20)". According to the American Music Therapy Association [26] music therapists assist the following client populations: developmental and learning disabilities; Alzheimer's and other aging related conditions; substance abuse problems; brain injuries; physical disabilities; acute and chronic pain. An accepted model put into practice within music therapy and neuroscience is Neurologic Music Therapy (NMT) [27].

Music listening and musical activities such as playing an instrument, induce neural plasticity in various brain regions, with an emphasis in frontotemporal areas [3, 28, 29, 30, 31]. Examples of effective music listening have been reported in the recovery of discharged patients after different types of major surgery. This is measured via indicators such as pain and anxiety level, use of analgesics and patient satisfaction [32], providing support that music may also enhance neurological rehabilitation [3]. Evidence exists for the use of auditory stimuli as an effective training stimulus during the rehabilitation of neglect. Significantly, the use of auditory stimuli enhanced visual perception during neglect rehabilitation studies [33, 34].

Based on the data of NMT, Musical Neglect Training (MNT) has been developed for patients with visual neglect [27, 35]. MNT is a (NMT) technique employed by music therapists that uses active musical exercises with participants. In the exercises, participants are required to play musical patterns (that can be melodic or rhythmic) on musical instruments that extend to the neglected visual field. The musical patterns should be well known to the participants to drive an attentional search in applying and completing music-related events in the neglected field.

#### VR Rehabilitation

VR is a technology that has been researched and subsequently utilised as an intervention for stroke and neglect rehabilitation. VR systems rely on computer hardware and software in creating and mediating interaction between the user and the virtual environment [36]. VR rehabilitation typically involves providing its user with visual-audio stimuli presented through a head-mounted device (HMD) to foster real-time feedback. Feedback can also be provided through the patient's senses (e.g., by movement, touch, or sound) [37, 38] by means of using different interaction devices. Thus, the patient can interact with these virtual environments utilizing different input (e.g., joysticks, cameras, sensors or haptic devices) [38].

VR rehabilitation has been noted for its ecological validity, with the technology's capability to simulate realistic environments in which stimulus control can support consistent repetitive delivery that is hierarchical [39]. Specifically, the feedback stimuli delivered by VR can appear graded and manipulated across multiple sensory modalities (e.g., audio, visual and tactile), as well as tailored to the goals of the patient, therapist and functional capability of the patient. VR application design and research with clinical populations has been focused on developing functional activities which can be completed safely. The activities are monitored with degrees of accuracy using kinematic tracking (i.e., motion capture) found in VR systems to provide a naturalistic record of the patient's bodily movement.

Limitations to VR rehabilitation are found in aspects of development and user experience. For example, finding the most suitable manner to use and interact with VR during rehabilitation is usually costly and time-consuming, depending on user testing [39]. VR applications may also lack clinical ease of use, with back-end data extraction providing raw data that is sometimes not accessible to healthcare teams. Then, there is the problem with VR's main stimulus delivery device, the HMD. While HMDs provide rich immersive experiences and stereoscopy, they are sometimes difficult for the user to use, tethered to a system by cable and provide a limited field of view. Side effects after using HMDs include, cybersickness and aftereffects. Cybersickness is a form of motion sickness, with reported symptoms in nausea, vomiting, eyestrain, disorientation, ataxia, and vertigo [40]. Aftereffect symptoms include flashbacks, drowsiness, fatigue, and perceptual-motor disturbances [41, 42, 43]. User eyestrain and headaches are also reported after using HMDs. The use of headphones with HMDs has also been reported as uncomfortable to wear for some users.

## VR Intervention Use for Neglect Populations

VR interventions for neglect rehabilitation have been developed, with studies tracking the upper-limbs of the patient using motion-capture technology related to task cueing stimuli [44]. The therapeutic goals associated with these interventions varied widely, with some using prism adaptation methods [45] removing parts of the ipsilesional visual field to promote contralesional orientation [46], and having patients reach for objects on the ipsi- and contralesional spatial side [47, 48]. In [47, 48], therapist support was given to some patients while they used the VR interventions. [44] writes that much of the visual stimuli used in these VR interventions was simple, using block shapes and colour to represent environments or task-related items the patient would interact with virtually.

## VR and MNT Adjunct Use

Given that neglect is typically a multisensory phenomenon, [6] recommends using sensory signals from different modalities to counteract the rightward bias in neglect patients. Adjunctive use of VR rehabilitation with MNT tasks may provide a music therapist and/or multidisciplinary healthcare teams with an effective multi-modal tool to include during neglect rehabilitation. This is because of VR's multi-modal capability that includes immersion in a virtual environment via visual and audio stimuli, access to motor tasks in games with applications simulating realistic bodily movement associated with ADL, a safe environment to practice rehabilitation, and its kinematic tracking capability using motion capture technology that may be applied to patient assessment.

#### Methodology

To construct this narrative review, non-systematic searches of the PubMed and PsycINFO databases were conducted to retrieve relevant articles, using English language restrictions. The data search included terms for virtual reality, neglect, music therapy, and rehabilitation.

## Selection Criteria

- 1. Study Type: Published peer reviewed primary studies.
- 2. Study Group: Patients (>18 years old) in a general hospital, family medicine clinics, sports medicine clinics, chiropractor clinics, physiotherapy clinics and/or

- rehabilitation clinics, with a diagnosis of neglect, hemineglect, spatial neglect, paresis and hemiparesis, using established diagnostic criteria.
- 3. Study Intervention: VR practice delivered/accompanied by specialists in physical medicine, rehabilitation, paediatricians, orthopaedics and physiotherapists. Music Therapy delivered by a Music Therapist (defined by possession of professional Music Therapy qualification and/or registered with the appropriate governing body).
- 4. Study Outcomes: Changes in stroke or neglect symptoms as measured by validated rating scales, clinical study report, case study report.

Articles deemed relevant to all authors, including randomized controlled pilot trials, VR rehabilitation effects on ADL studies, observational case studies, a neurologic music therapy study, VR rehabilitation used adjunctly with

physiotherapy, VR rehabilitation used with fMRI studies and feasibility trials were included. Data were examined and reviewed based on their clinical relevance.

### **Results**

## Topics and Study Designs

The study design results show one pre- and post- test design, three between group designs, two case studies, one between group design and within subject's design, and one quasi-experimental design: Non-equivalent control group design, one two-arm pilot RCT clinical trial. The largest study population includes 36 participants with the smallest study population including one participant (one case study). Information about the study designs and populations are summarised in table 1.

**Table 1.** Summary of the 9 studies reviewed, their objectives/goals, interventions, study designs, and study outcomes reported. Note the asterisks (\*) indicate intervention, assessment, and follow-up periods.

Study Title	Author(s) and Reference	Study Objective/Goals	Intervention	Study Design	Number of Participant s	Outcomes
Musical Neglect Training for Chronic Persistent Unilateral Visual Neglect Post- stroke	Kang and Thaut [49]	Spatial Neglect Symptoms	Musical Neglect Training *6-weeks follow up	Pre- and Post- Test Design	2	AT, LB *1-week follow-up
Rehabilitation in Chronic Spatial Neglect Strengthens Resting-state Connectivity	Wåhlin, Fordell, Ekman, and Lenfeldt [50]	Stroke severity, Awareness of physical sensation, Unilateral Neglect severity, Neglect severity, DAN Analysis, Brain Functional Anatomy	RehAtt*	Between Group Design	13	fMRI *1-week before intervention *1-week after intervention SCT, LB, BTT, VET, RBIT (VR-DISTRO). *1-2 weeks between assessments *1-week follow-up
Increase of Frontal Neuronal Activity in Chronic Neglect Training in Virtual Reality	Ekman, Fordell, Eriksson, et al. [51]	Stroke severity, Unilateral Neglect severity, Neglect severity, Awareness of physical sensation, Attention Behaviour	RehAtt®	Between Group Design	12	CBS, SCT, LBT, VET, BTT, PCT *PCT 1-2 weeks between sessions * fMRI scan 1-week before intervention and 1- week after intervention

Differing Effects of an Immersive Virtual Reality Programme on Unilateral Spatial Neglect on Activities of Daily Living	Yasuda, Muroi, Hirano, Saichi, and Iwata [52]	Visual Neglect severity, Unilateral Neglect severity, Stroke severity	Immersive VR programme	Case Study	1	LCT, LB, CBS.
Increasing Upper Limb Training Intensity in Chronic Stroke Using Embodied Virtual: A Pilot Study	Perez-Marcos, Chevalley, Schmidlin, et al. [53]	Motor Impairment, Awareness of physical Sensation, Safety of intervention, Patient Motivation	Mind- Motion ™ PRO	Between Group Design	10	FMA-UE, AROM, Muscle Strength, Functional Independence, Pain ratings, Safety and Acceptance of Technology, Tolerance to VR Intervention, Adverse Event Monitoring, Self-evaluation, Acceptance of technology, Motivation
Use of Virtual Reality In Improving Poststroke neglect: Promising Neuropsychological and Neurophysiological Findings From a Case Study	De Luca, Lo Buono, Leo, et al. [54]	Cognitive Impairment, Motor Impairment, Attention Behaviour	Bts-Nirvana System	Case Study	1	MMSE, Repeatable Battery for Neuropsychological Status, BIT, TCT.
Virtual Reality Application for the Remapping of Space In Neglect Patients	Ansuini, Pierno, Lusher, and Castiello [55]	Unilateral Neglect severity, Stroke severity	Hollow Box, Computer Monitor, DataGlove.	Between Group Design, Within Subjects Design	9	AT, SCT.
Virtual Reality Games as an Adjunct in Improving Upper Limb Function and General Health among Stroke Survivors	Ahmad, Singh, Nordin, Nee, and Ibrahim [56]	Motor Impairment, Patient Motivation, Patient functional independence, Stroke severity	Virtual Reality Games	Quasi- Experimental Design: Non- equivalent Control Group Design	36	FMA-UE, WMFT, IMI, IADL, SIS.
Feasibility, Safety and Efficacy of a Virtual Reality Exergame System to Supplement Upper Extremity Rehabilitation Post- Stroke: A Pilot Randomized Clinical Trial and Proof of Principle	Norouzi- Gheidari Hernandez, Archambault, Higgins, Poissant, Kairy [57]	Motor Impairment, Strokeseverity	Jintronix System	Two-arm pilot randomized clinical trial, pre-post follow-up design.	18	FMA-UE, BBT, SIS, MAL. *Baseline *Post-intervention *4-weeks follow up

#### Assessments

In all of the studies reviewed, various assessments are used to assess the patient's presence or severity of stroke and neglect symptoms. The different methods of assessment used are outlined below under the following categories: brain activity, computerised measures, standardized health measures and kinematic Tracking. Brain Activity was inclusive of Computed Tomography (CT), Magnetic Resonance Imaging (MRI), Functional Magnetic Resonance Imaging (fMRI).

The Standardized Health Measures included Activities of Daily Living (ADL), Albert's Test (AT), Behavioural Inattention Test (BIT), Barthel Index (BI), Catherine Bergego Scale (CBS), Fugl Meyer Assessment of Upper Extremity (FMA-UE), Functional Independence Measure (FIM), Intrinsic Motivation Inventory (IMI), Line Bisection Task (LB), Line Cancellation Test (LCT), Mini Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA), Motor Activity Log (MAL), Muscle Strength, Stroke Impact Scale (SIS), Trunk Control Test (TCT), Visual Extinction Test (VET), Wolf Motor Function Test (WMFT).

The Computerised Measures were Posner Cueing Task (PCT), Star Cancelation Test (SCT), Extinction Test (ET), Baking Tray Task (BTT), Rehabilitation Gaming System (RGS). Kinematic Tracking showed VR motion capture, Active Range of Motion (AROM).

## **Rehabilitation Strategies**

Rehabilitation strategies are referred to as the processes to how interventions function and what neurological and behavioral mechanisms they aim to engage during rehabilitation [49, 51, 57]. There are two different post-stroke rehabilitation

strategies. These are known as top-down and bottom-up. Top-down examples involve visual scanning training and visuomotor imagery therapy, while bottom-up techniques involve arm activation and prism adaptation training. Many of the existing top-down and bottom-up strategies and techniques have not demonstrated significant clinical efficacy, specifically for persons suffering with visual neglect [58, 59, 49]. Hence, there is a need for novel interventions to be used for neglect rehabilitation purposes.

One study [51] reveals what areas in the brain are typically stimulated most with top-down and bottom-up rehabilitation techniques. For instance, the Dorsal Attention Network (DAN) is a goal driven network, controlling spatial attention and stimulus selection and these are occupied with top-down rehabilitation strategies. On the other hand, the Ventral Attention Network (VAN) is described as a stimulus driven network, involved in reorientation, alerting responses and vigilance, and therefore, it is occupied with bottom-up rehabilitation strategies.

#### Interventions

In all of the literature reviewed, the two primary types of interventions used are VR and music therapy (specifically the MNT method of Neurologic Music Therapy). Some of the interventions are used as a primary mode of rehabilitation e.g., MNT in [49], VR in [55], VR in [52], and some of the interventions are used adjunctly with other modes of rehabilitation such as physiotherapy [57, 56] and standard cognitive therapy [54].

Descriptions of VR Applications, Devices and Games

**Table 2**. A description of the VR applications, devices and games used from the literature reviewed. The table reads horizontally from the authors (researchers who applied the VR applications) to the VR applications and games used in the studies, to descriptions of the studies.

Authors	VR Applications and Games	Descriptions
Ahmad, Singh, Nordin, Nee, and Ibrahim [56]	VR Games with Cy- Wee Z Game Controller	VR Games (including Mosquito Swat, Music Catch, Rebounce, Bejewelled, Balloon Popping, 10-pin Bowling, Air Hockey, Mah-Jong, and Solitaire) with Cy-Wee Z Game controller. The game controller is equipped with accelerometer, gyroscope and magnetic sensors enabling display of free movement in 3-dimensional space and capacity to detect depth.

Ansuini, Pierno, Lusher, and Castiello [55]	DataGlove	A VR controller (called DataGlove) with a computer program designed to allow neglect patients to reach and grasp an object, while simultaneously enabling the patients to observe the grasping of the virtual object in VR by a virtual hand. The virtual hand was controlled by their real hand which was placed in the DataGlove.
De Luca, Lo Buono, Leo, et al. [54]	Bts-Nirvana	Bts-Nirvana is a VR system connected to a projector or a big screen, reproducing a series of exercises. The system analyzes the patient's movements to create interactivity. Audio-visual stimuli produced from the system are presented on both sides of the virtual environment.
Ekman, Fordell, Eriksson, et al. [51]	RehAtt*	RehAtt® involves the patient to complete intense scanning activities, with levels of the game adjusted according to the patient's difficulty. The RehAtt® environment is also enhanced by sound, visual and vibrotactile stimuli which are integrated in the game. The patient's contralesional hand controlled the 3D game using a force-feedback robotic pen.
Norouzi-Gheidari, Hernandez, Archambault, Higgins, Poissant, Kairy, [57]	Jintronix	The Jintronix application is used by therapists to record a patients' physical activity and adjust the difficulty of a motor task.
Perez-Marcos, Chevalley, Schmidlin, et al. [53]	MindMotion PRO™	A VR-based system used for rehabilitation of the upper limbs after brain damage. Exercises of the MindMotionTM PRO™ are presented in game-like scenarios designed to increase patients' motivation and therapy dose. A motion tracking camera and touch with an embedded computer is included. The 3D motion tracking camera captures participant's movements, and quantifies upper limb and trunk joint angles using passive colored markers
Yasuda, Muroi, Hirano, Saichi, and Iwata [52]	Immersive VR Program (including a motion-tracking device called Leap Motion)	The Immersive VR program is a 3D room environment, in which a desk is seen. In front of the desk a virtual screen is placed and seven visual stimuli. Three objects are placed on the table in the VR space. The patient moved their right hand freely and was able to see their hand in the VR space. When the VR hand touched an object, the object turned red. To draw attention to the left side in the VR environment, they included a moving slit and slowly drew the projected image seen by the patient towards the left.

## MNT Method of Neurologic Music Therapy

MNT emphasizes left-field visual processing by using musical exercises on music making equipment. MNT uses active musical exercises structured in pitch, time and tempo, using musical equipment purposefully configured to focus active attention toward the neglected field [49]. Theoretically, the combination of spatial orientation and motor execution in the perceptual and physical set up of MNT is a crucial component of the intervention, as it addresses these processes together.

In the study by [49], participants sat in a chair and played tone bars placed on the desk by using their non-paretic arm (right arm). The first tone bar (D) was placed toward the centre

of the participants, (which was also aligned with the midsection of their faces). Following this, two tone bars (B, C#) were set to the right side before starting a scale or triad in order to begin the playing movement from right to left side. The participants followed five protocol levels by playing three ascending scales to full scale. A hi-hat cymbal was placed in the final position to provide a strong sound for completion of the pattern. In each pattern, the cymbals' edge matched the end of the very last tone bar's edge. The researcher was positioned on the patients nonneglect side (their right side) to provide instruction and play a keyboard accompaniment for each pitch. The participants repeated these patterns five times before moving to the next level.

#### Intervention outcomes

## Musical Neglect Training Outcomes

MNT was used on two individuals with chronic visual neglect. These participants underwent six individual MNT sessions. Two standardized health measures were used on the participants, the AT and Line Bisection test [49]. The AT tests for visuo-motor neglect, while the Line Bisection test tests for egocentric perceptive neglect. The findings show significant improvements from pre- to post- intervention on one outcome measure, which was the AT, indicating improvement in visuo-motor neglect.

## VR Rehabilitation with Daily Living Outcomes

[52] tested VR technology on a patient with near and far spatial neglect, evaluating if the VR application had an effect on the patient's ADL. They reported an improvement on post-stroke symptoms in tests assessing near and far space neglect (LB, and LCT) in their single participant. However, the study found no change in the patients' CBS scores that were used as a measure of ADL throughout the intervention period. The results of the study suggest the participant unsuccessfully translated visual search task skills used in spatial detection to ADL, thus the VR intervention had little effect on ADL. Despite this, the results in symptom improvements of the study are described as replicating previous findings, indicating the immersive VR intervention is beneficial for performing visual search tasks in cases of far space neglect.

### VR Rehabilitation with Neurological Outcomes

[51] used functional magnetic resonance imaging (fMRI) scanning before and after patients used a VR intervention designed for neglect rehabilitation with the aim to evaluate if clinical improvements could be seen in chronic neglect after rehabilitation sessions. In addition, the team aimed to evaluate if such changes were represented by changes in neurological attention networks and in other areas.

Following a neuroimaging evaluation, results from the study indicate that regions of a neglect patient's brain are affected in a potentially beneficial way after training using a multisensory VR intervention for rehabilitation. Specifically, results show an increase in the neglect participants' taskevoked brain activity after the VR intervention was used for rehabilitation sessions. The brain regions activated include the prefrontal and temporal cortex during attentional cueing. Correlations were also found between brain and behavioural changes during use of their VR intervention and monitoring via fMRI scanning. The data show blood oxygen level-dependent

signal (BOLD) signals in the brain increase as their patients (who have neglect) use their VR intervention for rehabilitation. This neurological activity correlated with behavioural improvements, reporting increased cue-induced focus of attention, found in the prefrontal cortex, bilateral middle and superior temporal gyrus after 15 hours of training.

The same team [50] used fMRI scanning to explore neural mechanisms associated with recovery and neglect. They present data on resting-state functional connectivity within the DAN in chronic neglect patients undergoing rehabilitation using VR, aiming to improve left-side awareness. The fMRI results from this study indicate that as patients completed training using a VR intervention, a region responsible for saccadic eye movements to the left became more integrated with the left posterior parietal cortex. In addition, fMRI scanning showed results indicating a longitudinal increase in interhemispheric functional connectivity between the right frontal eye field and left intraparietal sulcus following VR rehabilitation. Further analysis revealed that VR rehabilitation influenced DAN connectivity more than other networks. This is highlighted as potentially a new mechanism that can be used during the rehabilitation of patients with visuospatial neglect.

### VR with Motor and Physical Rehabilitation Outcomes

[53] investigated upper limb function using VR as an intervention for post-stroke rehabilitation. The study reported findings in a high-efficiency rate (the relationship between the time of a therapy session and the time spent in active therapy) of 86.30% in favour of the VR intervention, as well as improvements in FMA-UE and AROM scores of the patient. No changes were found in the patient's functional independence. FMA-UE was tested at post-intervention and AROM was observed at follow-up. The results of this study conclude that task-specific VR training may be advantageous for motor recovery in stroke survivors.

To investigate upper limb motor function in stroke survivors, VR was used by [57]. They reported outcomes favouring the VR technology (M = 1.0%, 5.5%, and 6.7% between the intervention and control group, post-intervention) when compared to traditional stroke therapy (e.g., physiotherapy and occupational therapy). Furthermore, the study reported VR gamification technology as feasible and safe during post-stroke rehabilitation.

[56] studied the use of VR games (including Mosquito Swat, Music Catch, Rebounce, Bejewelled, Balloon Popping, 10-pin Bowling, Air Hockey, Mah-Jong, and Solitaire) applied adjunctly to traditional stroke therapy (e.g., physiotherapy) on a stroke population. The results report no significant difference between VR and traditional therapy interventions (e.g., physiotherapy).

## VR with Cognitive Rehabilitation Outcomes

[54] used a VR system called Bts-Nirvana on a single patient suffering with USN. [55] demonstrated a significant improvement on a USN patients' motor and cognitive function. In addition, a minor improvement in the patients' mood is found, with a reduction in depression.

#### Discussion

## Focus of the Study and Commentary

The focus of this review was to summarise evidence of existing interventions and assessments used for post-stroke and neglect populations in VR and music therapy research. The review includes studies that employed VR and MNT as interventions for post-stroke and neglect rehabilitation. In general, the authors came to similar conclusions as shown in other studies in this field [1, 7], with the exception of the fMRI scanning of neglect patients during the use of VR [51, 52]. This review is in line with [1] and [7] commentaries regarding the use of novel interventions in post-stroke rehabilitation studies. They argued that promising findings are found in smaller trials but appear more difficult to reproduce in larger ones. Such findings are abundantly clear in this review, where pilot studies, case studies and feasibility studies were reviewed but larger studies could not be identified. For instance [57, 56, 53, 54, 55], all produce positive findings in safety and feasibility regarding the use of VR for stroke and neglect rehabilitation. Yet, the efficacy of their interventions requires further investigation in larger trials. This finding is also emphasised in the MNT study. The number of participants involved in the studies was relatively small, with a maximum participant total of 36. In addition to small sample sizes, most of the study designs pose challenges to the integrity of the findings. Furthermore, no large scale RCT was reviewed.

This review highlights promising neurological outcomes seen in [51] and [50] studies, finding stimulation of specific neurological regions during exposure to a VR intervention in neglect patients. Specifically, [51] found the neurological activity in the prefrontal cortex, bilateral middle and superior temporal gyrus correlate with behavioural improvements, transferring to increased focus of attention. While [50] reported DAN activity of neglect patients as being positively influenced during exposure to VR rehabilitation, transferring to saccadic eye movement to the left becoming more integrated with the left posterior parietal cortex. [7] points out that such data is crucial for future study due to a lack of understanding of the neurological mechanisms that can be exploited during neglect rehabilitation. Yet, the sample sizes used in these

studies are small, and the challenge remains to investigate their results in a larger trial. It is also unclear if the patients reported outcomes specific to the intervention used in both studies (i.e., RehAtt\*).

The heterogeneity of the interventions reviewed during neglect rehabilitation make it difficult to assess their evidence with clarity, echoing findings from [1] scoping review. The lack of consistent selection of assessments used make it difficult to evaluate which intervention was most effective on its population and why. Indeed, the studies reviewed had a reliance on standardized assessments which are not neglect specific. This confirms findings from [7] review, that the general lack of common standards in this field obscures its findings.

## Study Goals and Outcomes

Another reason for the lack of high-quality evidence could be that the goals of the studies were not consistently aligned in reducing disabilities and improving independence. Instead, they were focused on aspects pertaining to the feasibility (if the interventions functioned correctly or not) in using the interventions in post-stroke and neglect rehabilitation. [58] argues that the focus of studies in post-stroke rehabilitation should be in reducing disability and improving independence, rather than testing if interventions function or not. To demonstrate this, [52] reports that VR tasks used for neglect did not transfer to improvements in ADL outcomes, yet argued for the feasibility of their Immersive VR Program when used with neglect patients. Thus, the efficacy of the VR application is not promising when associated with daily living outcomes.

On the other hand, the review broadly points to preliminary evidence that VR used as an adjunct intervention for neglect rehabilitation with physical and occupational therapy practice is beneficial. This is indicated in the studies conducted by [56, 57, 53] who combined VR with physiotherapy, occupational therapy and physical therapy rehabilitation, producing positive therapeutic outcomes.

## Exploring VR's purpose as an Adjunct Intervention in Music Therapy Practice

For VR to be used as an adjunct intervention during neglect rehabilitation by music therapists, its relevance for music therapy practice requires further examination. First, the lack of clinical evidence from this review to support the inclusion of VR technology with established music therapy practices, does not imply immediate adoption by music therapists. This suggests that acknowledgment of this review's results are used as a preliminary guideline to how VR can be applied to outcomes associated with music therapy practice. Second, the

clear benefits in using VR adjunctly with music therapy practices must be developed. Third, using VR adjunctly with music therapy practices must be done in a safe and feasible manner. In order to investigate this, music therapy must be placed in a multidisciplinary context, acknowledging the healthcare practices which have previously used VR for different purposes. Therefore, the remainder of this review will briefly explore potential intersecting areas of research, as indicated from the results in relation to VR and music therapy rehabilitation, which may be applied to neglect rehabilitation.

## Intersecting Purposes in VR and Music Therapy Interventions

Based on this review's findings, we explore how VR and music intervention purposes intersect in similar areas during neglect rehabilitation, such as the music therapist utilising VR for assessment purposes. We also discuss the multimodal capabilities of both interventions. Specifically, we consider VR's kinematic tracking capability as a motor assessment instrument that can be utilised by the music therapist, as this provides clinical data regarding the patient's limb movement based on practice. Furthermore, the multimodality of the intervention can be given importance due to its support in rehabilitating the multiple areas of dysfunction caused by neglect [9, 12, 8, 6, 11, 10].

#### Assessment

As indicated by use of the MindMotion PRO™ by [53], quantitatively tracking a neglect patient's kinematic behaviour (e.g., motor movement of the limbs) to audio stimulus during VR usage provides feedback about the patient's limb movement. This could be applied to music therapy sessions, measuring the range of motion and training intensity during music therapy sessions in order to provide real-time feedback to support music therapists regarding intervention outcome. Specifically, this feedback supports an accuracy in motor assessment, allowing for the therapist to observe the effects (or lack of) of the audio stimulus on a patient's motor movement during, between and after sessions.

## Multimodality

A multimodal approach to rehabilitation sees multiple approaches contributing to a therapeutic process. Multimodality highlights the multidisciplinarity of a rehabilitative protocol or treatment plan. By focusing on common aims of each discipline, or how the work towards these aims can contribute to one another, treatment becomes streamlined and cooperative. If therapists could combine the use of VR and MNT during neglect rehabilitation, there is the

possibility to address neurological, physical, and perceptual needs of a patient simultaneously within one therapy session.

Initially, thorough assessment would be needed to determine the suitability for such an intervention. This would likely require involvement of physical therapy, occupational therapy, and music therapy. It is possible with future research that a specific multidisciplinary assessment tool be established for use of this intervention specifically, to determine patients' suitability. When considering implementation of this intervention, it is feasible to consider that with the proper safeguards and training in place, this proposed method of rehabilitation could be implemented as an adjunct intervention for rehabilitation by music therapists, physical therapists, or occupational therapists. This aspect would need to be addressed in future research, in formal development and evaluation of the clinical protocol. Some of these safe-guards are embedded in the VR application experience, which allows the user to safely participate in task-based activities without the risk of dysfunctional movement within a real-world setting as well as the considerations of cybersickness and aftereffects [40, 41, 42, 43]. However, future training among professionals will be crucial, especially regarding safety in physical rehabilitation, competence training in using VR in practice, needed when using music interventions.

For the patient, the collective work towards common aims and a streamlined process seen in a multimodal approach to rehabilitation could result in fewer appointments over time. This would ideally result in cost savings for the patient, in addition to the reduced time spent in, and traveling to, appointments.

## *Intersecting Purposes Outside this Review*

Evidence not accounted for in the outcomes of this review includes intersecting purposes between VR and music therapy interventions associated with restoring function in damaged areas of the brain caused by the stroke with motivating taskbased activity. Both interventions contain purposeful activity (task-based or movement induced) by focusing attention or inducing movement toward the left side of the patient (e.g., inducing patient motor movement to the left side, having the patient look toward the left side, or play musical tone bars toward the left side) to make rehabilitation enjoyable, as well as maintain patient adherence to the rehabilitation. This psychosocial aspect of patient adherence and motivation to rehabilitation is regularly discussed in the background literature of the articles reviewed, but not accounted for in the study outcomes. Therefore, we discuss patient adherence and motivation to neglect rehabilitation below as an intersecting purpose of VR and music therapy interventions for neglect rehabilitation.

Task-based activity, Patient Adherence and Motivation to Neglect Rehabilitation

The experience of music is known to have not only an emotional role, but also a motivational role. The music component itself in music therapy practice has been proven to contribute to specific motivating neurobiological systems and mechanisms, activating the dopaminergic mesolimbic system, while regulating mechanisms in memory, attention, executive functions, mood and motivation [3, 60]. Dopamine plays a significant role in the neurobiological workings of reward, learning, and addiction. Naturally occurring rewards, such as positive music experiences, activate these dopaminergic systems and contribute to one's attention and learning [62]. Furthermore, the multimodal activity of music through engagement or creation supports plastic changes in the nervous system [19, 23, 24].

Following this, the music component within an intervention is a large part of what motivates the patient to complete a task, work towards goals, and/or to actively participate in the work with the music therapist. Much like the inclusion of VR in neurological rehabilitation, music interventions also provide an added purposefulness to the activity. A patient's motivation towards rehabilitation exercises is critically important, as these exercises can seem repetitive, and at times uncomfortable. Adding a purposeful element to the rehabilitative exercises contributes to patient motivation [62].

As illustrated in this review, both VR and music therapy interventions produce recovery in domains afflicted by neglect, with VR providing some evidence in improving patient adherence to treatment. It is conceivable then, that by combining a purposeful music intervention with an already motivating rehabilitation environment by using VR, that rehabilitation and progress towards aims may be somehow streamlined or further beneficial for patients and healthcare systems alike.

#### Limitations

As previously outlined, there are challenges to generalising the findings from this review, due to small trials, small sample sizes, heterogeneous assessments, goals, and outcomes. This implies the need for caution when interpreting any evidence reviewed for use in clinical settings. Similarly, some of the studies reviewed here are not directly applied to the treatment of neglect but are primarily investigating feasibility of the interventions.

Due to the narrow scope of this review, there are many opportunities for further inquiry. This includes understanding

in greater detail the function of neurological mechanisms of neglect patients when exposed to VR and music, and then designing interventions around beneficial neurological exploitation. There is a need for a rigorous practical understanding of how to use VR in neurologic music therapy settings, and the development of a formal clinical protocol will be needed. Furthermore, the costs of VR equipment may also burden some music therapists and multidisciplinary teams, and how these equipment costs can be justified without rigorous clinical evidence remains unclear.

#### Conclusion

In this review, the use of VR during stroke and neglect rehabilitation produces findings regarding feasibility and safety, however the clinical findings are ambiguous. Larger trials with similar assessments are needed to arrive upon generalisations. Promising neurological outcomes were found in stimulation of specific neurological regions during exposure to a VR intervention in neglect patients. Specifically, neurological activity in the prefrontal cortex, bilateral middle and superior temporal gyrus was associated with increased focus of attention during VR rehabilitation. In addition, saccadic eye movement to the left became more integrated with the left posterior parietal cortex during VR rehabilitation.

Based on the review's findings, the authors explored how VR and music-based interventions purposes intersect in similar areas used for neglect rehabilitation. These are in assessment, patient adherence and motivation to treatment, as well as the multimodal capabilities of both interventions. Using VR and music-based interventions adjunctly for neglect rehabilitation is theoretically promising, and development of a clinical framework to practically use these interventions with neglect patients is suggested.

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Full-Length Article

## An International Discourse on 'Music and Medicine' Efthymios Papatzikis<sup>1</sup>

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#### Abstract

The 7th International Conference of the International Association for Music & Medicine was held on May 28 - 29, 2022. Meetings and presentations from Greek and international invited speakers took place in person and through live streaming May 28 to May 29, 2022. Additionally, a week of online-only presentations took place May 30 to June 3, 2022. Athens is one of the world's oldest cities, offering centuries-old history to be explored and enjoyed. According to Plato, one of the first schools of music education was founded by the people of Crete followed by the musical schools of Athens, where students were taught to sing and play the lyre. Many delegates from across the globe were honored to meet in this magical and historical city. Below, conference delegate Dr. Efthymios Papatzikis reviews and reflects upon some of the conference highlights.

Keywords: IAMM, Conference, Music and Medicine

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Since antiquity, music's role in addressing illness is noteworthy. Approximately, 35,000 years ago we find evidence of music being used in healing rituals [1], while much later, Pythagoras, in the 6th century BC, in Ancient Greece, has been historically considered to be one of the first to systematically employ music to treat disease [2]. In the same vein of practice, both Hippocrates – the father of medicine – and Aristotle, a few centuries later, used music as a vehicle to approach and treat bodily and psychological ailments. Of course, we are not short of examples in the years, decades, and centuries, that followed-showcasing the importance music has played, as a valuable tool to support and augment healing [3].

Fast forward to our contemporary time, and while not yet fully 'tamed' or understood at a precision level as perhaps other tools, or methodologies employed in a clinical context, music is still strongly infused and embedded in the practice of medicine, with a growing number of clinical and academic institutions significantly investing in its admitted 'power' and its rendering of evidence-based results. In this manner, practical follow-ups on its historical dynamics show music's efficacy that often supports pharmacological and non-pharmacological interventions in improving health and well-being.

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Efthymios Papatzikis PhD, E-mail: <a href="mailto:efthymio@oslomet.no">efthymio@oslomet.no</a> | COI statement: The author declared that no financial support was given for the writing of this article. The author has no conflict of interest to declare.

In this context, and in a continuous effort to convey knowledge and present the state-of-the-art of the Music and Medicine scientific field, the 7th International Conference of the International Association for Music and Medicine (I.A.M.M.) took place in Athens, establishing for seven full days the domain's beating heart in Greece. The conference was held between the 28th of May and the 3rd of June 2022 in a double hybrid format — with two days of physical presentations inclusive of online worldwide broadcasting and five days of online-only presentations with worldwide broadcasting. It was attended with undiminished interest by more than 400 delegates from all over the world.

During the Conference, four keynote speeches were presented by distinguished professionals and scholars, including Dr Athanasios Dritsas, Prof. John Ioannidis, and Profs. Joanne Loewy and Athanasios Fokas. These presentations covered the topics of the Music's Role in Exercise, Research Reproducibility and Transparency in Music and Medicine, Integrative Therapies in Music and Music Therapy in Medicine, as well as Music and the Unconscious, setting in this way a much-needed interdisciplinary scope on the content of the conference.

There also were three round tables, organized by esteemed scientists from many different parts of the world. The round tables' discussions ranged from initially bringing up the *Biology and Psychoanalysis on Music* topic, continued by elaborating the *Cosmic Harmony, Creation and Art* idea, while concluding with a more technical discussion on neuroscientific, multimodal (fMRI, fNIRS, EEG-ABR) approaches on how to study newborns in clinical contexts (*Music and Brain Studies*)

on Newborns). In total, more than 150 presentations and posters, eight workshops, eight Special Interest Groups and a Plenary Session populated the full week, covering multidisciplinary, multi-modal thematic content on how music lives or could live in the medical practice, and how its benefiting potential can be harvested in the clinical, psychological, neurorehabilitative and neuro-developmental contexts. Noteworthy also was the pre-conference neonatal intensive care unit (NICU) training, which brought music therapists, physicians, and clinicians together to partake in Tier I of the First Sounds: Rhythm, Breath, and Lullaby. This training focused on both the theoretical and practical aspects of music therapy in the NICU while delivering opportunities for participants to approach hands-on and observe the contextual parameters and biopsychological procedures taking place for pre-mature infants right at the hospital in the Helena Venizelou NICU.

Although the binary format of the conference was risky in terms of organization - it deemed to be a wise choice in protecting public health from the risk of spreading COVID-19 coronavirus disease at this time. The mixture of optional live or virtual attendance seemingly allowed for provisions of inclusion, that many more delegates could access and enjoy the content of the conference, in the manner they chose, amidst a still slow aftermath of pandemic concerns. Of course, it seemed like a quite difficult task for the I.A.M.M team to bring into fruition. And for this, the conference Chairs, Thanassis Dritsas and Vera Brandes, along with the rest of the organization committee should be applauded. On the one hand, due to the intense experiential and interactive nature of all the previous conference needs they had to consider, and on the other hand, due to the task of juggling the high-level of technical requirements that were embedded in bringing to fruition such an extensive and complex conference structure. Despite any difficulties and challenges, the binary format seemed to work smoothly and better than expected as captured by the interest of the many delegates in attendance.

The extensive participation and worldwide inclusion certainly brought a feeling of content in the aftermath of the online part of the scientific gathering, too, realizing that even the most difficult part of the conference – the artistic activities – was successfully conveyed both on-site and online, respectively. The conference included two coffee concerts, one by the baroque violist, Hanna Pakkala, and a second by the violinist Katalin Kertesz, as well as a fantastic concert demonstration on ancient Greek instruments by *Les Lyristes*. These performances, within the schedule, strategically seemed to link the past with the present, the divine with the orthological, the desired with the evidence-based knowledge, bringing in this way the worlds of music and medicine together in the best possible interdisciplinary manner and framework.

Like any other field of interdisciplinary science, music and medicine comprise a dynamic partnership between various professions, multi-faceted knowledge, and related practices. In this vein of understanding, during the proceedings, a particular emphasis was placed on the intersectional goals that musicians and physicians can achieve in this interdisciplinary scientific field to benefit patients. Thus, and as expected, the profound contribution of music therapy was communicated as a primary professional path in the field which successfully brings music into the medical practice. On this very basis, various manifestations of music therapy studies and projects were fervently presented, bringing to the fore, research on musicbased interventions; for movement disorders; telehealth music and psychotherapy services; community music pedagogies and engagements in healthcare; on music-based practices in the NICU; assessment in music therapy; music's role to manage and soothe chronic pain; music's potential to provide quality time and a sense of well-being for patients with dementia or trauma - to name a few.

It should be also mentioned that particularly emphasized in the overall presentations and discussions was the need for constant vigilance and attention toward infusing more fundamental methodological and technical knowledge into the framework of music and medicine in professional practice. The assertion of studying more the fields of neuroscience, biology, pharmacology, psychology, psychiatry, and sociology in connection to music was accepted as of paramount importance. This is essential as we consider the emerging deep infiltration the growing field of music and medicine has been showcasing especially within the last few years in clinical, academic, and wider arenas such as within social contexts (i.e., seen as medical practice, medical education, or social contribution respectively). In this direction, the practical support of the official education institutions and states are growing in willingness, agreeing to be a fundamental factor of advancement and stability in the music and medical field. This is exemplary and will further allow for the establishment and continuance of more viable research projects, thematic pluralism, and dialogue in what needs to be achieved. It was also pointed out that recruitment of more interdisciplinary, yet methodologically clear specialization is needed to reach precision and sustainable medical outcomes.

Overall, the proceedings of the 7th I.A.M.M. International Conference helped to consolidate present themes, as it captured the experiences, concerns, new trends and knowledge that appear in the clinical, academic, and social contexts of the interdisciplinary framework of music and medicine. And in light of this, the presentations were approached and received as having a direct impact on the patients' and healthcare provider's everyday life, with healing expectations, intentions, and well-being. By this token, the impossibility of any secure

prediction for the future, and the dystopian age we live in, make scholarly efforts like this an extraordinary 'springboard' to step on for trying to advance the field's inclusion in society. As result, some new weight in the conference's benefiting oeuvre was assigned, following what was admittedly seen in general for the specific scientific field's contribution all over the world throughout the COVID-19 pandemic, too. As the President of the I.A.M.M. - Dr Suzanne Hanser - said, "given the many challenges facing all of us around the world, we are most grateful that the in-person portion of this year's conference was able to take place here in Athens, Greece and that we could gather together at last. And now, as the world begins to emerge from the pandemic, I am convinced that I.A.M.M. has a significant role to play in bringing music and harmony more integrally into our lives. We are the people who apply music in the service of health, medicine, and wellbeing - we are the people who offer beauty and awe at times of uncertainty - we are the people who are committed to fill the lives of others with salubrious music. May we all combine our various professional backgrounds, cultures, abilities, and talents, as we explore opportunities to enhance creativity, communication, and wellbeing through music. We understand so well how music can serve as a conduit for healthier, more peaceful, and joyous living. Building on the diversity of our perspectives, specialties, and models within our global community, many of which were represented at this I.A.M.M. 2022 International Conference, I.A.M.M. members are in a position to participate in the new world order, whereby music and the arts will not simply come back, but become

essential – bringing meaning, empathy, self-expression, togetherness, awe, and beauty to a post-COVID era. May we live this vision through our collaborations and colleagueship."

Wanting to reach and study the proceedings of the 7th I.A.M.M International Conference in more detail, one should know that all presented material is hosted on the official I.A.M.M. website for two years since the conference's conclusion [4]. In the meantime, the entire Music and Medicine community awaits with a force of optimism and dedication the next official meet-up taking place in the next couple of years, to further enjoy and declare advancements in the field.

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Book Review

# Relationship completion in palliative care music therapy Editors: Amy Clements-Cortes & Joyce Yip

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Relationships are significant in end-of-life care. Music therapy research and descriptive writing have built a body of knowledge supporting efficacy, enabling clinicians to implement evidence-based practices in their work. While relationships and relationship completion have been studied in end-of-life care, there are no written guidelines based on the best practices of relationship completion in palliative care music therapy. Thus, this is the impetus for this book.Relationship Completion in Palliative Care Music Therapy provides foundational information on relationships, relationship completion in end-of-life care, locations of care, and the scope of the continuum of music experiences. It is written by an international group of experts who collaborated over two years to develop this resource. With particular attention to the importance of equity, diversity, and inclusivity, intercultural competence and anti-oppressive practices are threaded throughout the text with a focus on music therapy techniques for the patient and caregivers. Step by step guidelines are provided for work with children and adults, which are divided into receptive, improvisational, compositional, and recreative categories. Further, a chapter on education and training guidelines is provided, alongside considerations in end-of-life care such as funeral planning, medical assistance in dying, dying alone, and bereavement. This text is a must-read for clinicians, educators and researchers working with the dying and bereaved.

Keywords: End of life; end of life care; palliative care; relationship completion

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Relationship completion is a relatively new area of focus in palliative care that is of growing interest and championed by Dr. Amy Clements-Cortes. This book includes a collaboration of music therapists whose work is inclusive of various models of palliative care, in settings around the world. It is a strong read not only clinicians, but for students, researchers, and others in allied health professions.

Dr. Amy Clements-Cortes, an active member of the International Association for Music and Medicine (IAMM), assembled the authors who included practices and unique outcomes of music therapy, with a theme of relationship completion threading significance in end-of-life care. Dr. Clements-Cortes, together with Joyce Yip, organized a truly international group of experts: Dr. SarahRose Black, Sara Klinck, Chrissy Pearson from Canada; Dr. Lucy Forest from Australia; Dr. Joanne Loewy, Dr. John Mondanaro, Dr. Andrew Rossetti and Brian Schreck from the USA; Marija Pranjic (Croatia-Canada) and Dr. Giorgos Tsiris from the UK.

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According to Clements-Cortes, this book aims to provide written guidelines for music therapy and relationship completion. The prelude (p. xvii) lists and defines the following 10 types of music experiences: environmental music, music for entertainment, recreational, community music experiences, music ensembles, music education and lessons, music medicine, music thanatology, music therapy, and the Environmental Music Therapy (EMT). The book is divided into two parts: more introductory, theoretical, philosophical part (chapters 1 through 8), and a practical part with clear guidelines for working with the adults (chapters 9 through 13) and children (chapters 14 and 15), with a conclusive chapter on Medical Assistance in Dying and Bereavement.

In Chapter 1, the authors Clements-Cortes, Klinck, Forrest, and Yip explore intrapersonal, interpersonal, and transpersonal relationships and the relationship with one's home, country, culture, and community. These relationships are at the forefront of end-of-life care- as human beings belong and connect with others. "Separation from home, family, community, culture and land may become a source of anxiety, fear, grief, and loss" (p. 7). The authors cite Dr. Ira Byock's five essential sentiments that facilitate relationship completion: "I love you," "Thank you," "Forgive me," "I forgive you," and "Good bye" (p. 10). Clements-Cortes wrote (p. 10) that being

close to the end of life intensifies feelings of love, thankfulness, regrets, and forgiveness.

Chapter 2, by Klinck, Forrest, and Tsiris, discusses the importance of various care locations and music therapy in community palliative care. Music therapists may work in hospitals, homes, hospices, and residential care facilities. The authors inform readers of the importance of community engagement in palliative care, emphasizing that bringing people together in hospices can create a place of "comfort and reflection" (p. 19) and thus supports relationship completion. The authors provide a detailed reflection on the benefits and challenges of community palliative care. They point out the added challenge of patients' movement between the settings that can both help and interrupt the relationship completion process.

In Chapter 3, Yip, Clements-Cortes, Pranjic, and Tsiris discuss the scientific evidence of various music experiences such as recreational music, entertainment, and music and medicine. The authors describe research on both adults and children in end-of-life care, pointing at these interventions' potential "to transform the environment and people's experience [...] and enhance people's sense of connection and their engagement in relationship completion work" (p. 29).

Chapter 4 (Klinck, Clements-Cortes, & Black) outlines the interventions that include receptive, improvisational, compositional, and re-creative music therapy and the unique goals that music therapy can help address. Among the receptive methods (interactive listening), the authors' included song song dedications, song legacies, choice, discussion/analysis, music for reminiscence, entrainment, and the Bonny Method of Guided Imagery and Music. Among the improvisational methods, they included the following: empathic improvisation, active vocal/instrumental improvisation, free associative singing, and environmental music therapy (EMT). Finally, in the compositional methods, the authors describe the potency of song composition, songwriting, musical autobiography, and musical life review.

Chapter 5 by Clements-Cortes, Black, Yip, Pranjic, Schreck, and Rossetti discusses the evidence and potential for relationship completion with adults as well as children and intergenerational music therapy. There is support for receptive music therapy (including for Medical Assistance in Dying, or MAiD), improvisational and compositional, and Environmental Music Therapy, but no literature on re-creative music therapy. Overall, there is less literature on palliative care music therapy with children including for the purpose of relationship completion.

Chapter 6 explains the potential of the Bonny Method of GIM in relationship completion. Clements-Cortes is a well-known researcher on this particular topic. Together with Yip, they provide a short but detailed explanation of the application

of the GIM programs in supporting relationships and their completion.

Chapter 7, written by Loewy, stands out in the way it is written: the author uses first-person language in writing a case study about her professional experience working on relationship completion with an unexpected death during the early phase of COVID-19 trauma. It is not theoretical like the previous chapters and reads on one go. Joanne wrote about a long time client she saw in individual therapy and also in a group choir context. An emphasis of holding "a unique place for possibility in its capacity to ignite the human spirit and the love we all share" (p. 70) and doing it most meaningfully before and after the passage of death for all involved people, was highlighted in her use of music therapy for relationship completion.

In Chapter 8, Mondanaro and Tsiris provide a detailed analysis and suggestions for contemporary education of music therapists in palliative care. They stress the importance of keeping current with the contemporary palliative care orientations. I especially liked their focus on spiritual and cultural considerations. The authors suggest "an in-depth exploration of spirituality and its connection to people's experiences of relationship completion" (p. 78), which should go alongside students' exploration of their spirituality to know their own beliefs and comfort and discomfort zones. Sociocultural awareness is also essential for culturally sensitive practices. Another necessary change proposed by the authors is focusing not on the "effectiveness" of music therapy for clients (p. 80) but its impact on families and organizational systems, as music therapy methods can facilitate relationship completion and grief processing of everyone who experienced losses of patients/ clients.

Chapter 9 (Klinck and Clements-Cortes) informs readers about how to introduce relationship completion in adult palliative care. The authors explain who should do it, how, and when it should occur, and they also provide a list of questions to explain relevant to introducing relationship completion and what it should look and sound like. The authors listed various considerations in undertaking relationship completion, such as individual, family, culture, community, practical, logistical, and ethical considerations.

The following four chapters, written by Pearson (10, 12, 13) and Klinck (11), include detailed guidelines for relationship completion in adult palliative care. They all have a similar structure, starting with the assessment/when to use a particular technique, followed by goals, preparation, procedures, observation with ongoing assessment, and adaptations, with the addition of ethical considerations for specific techniques. I found this structure very easy to follow and think that these chapters could be used as a required text in training programs, particularly to prepare students for practical and internships in palliative care and hospice.

The chapter on receptive methods outlines details about music listening, song/music discussion and lyric analysis, relaxation and entrainment, song choice and personalized playlists, reminiscence, and The Bonny Method. In a chapter on improvisational music therapy, Klinck discusses empathic improvisation, active vocal/instrumental improvisation, toning, free associative singing, and Environmental Music Therapy. The final chapters on compositional and re-creative methods follow the same format.

In Chapter 14, Forrest outlines relationship completion and provides key considerations that are relevant to working in pediatric palliative care (PPE). She explains when to introduce relationship completion, and provides a detailed table of direct and indirect approaches to initiate relationship completion (pp. 172-174), reminding us about cultural considerations and how for some families, "there may never be a sense of completion or resolution" (p. 175). Forrest offers another valuable table, "Developmental stages and music therapy goals" (pp. 177-178), which gives clear guidelines on the goals and possible music therapy interventions.

In Chapter 15, Forrest discusses guidelines for receptive, improvisational, compositional, and re-creative methods, with the same structure we saw in the chapters on relationship completion with adults. It is another valuable "textbook" chapter with practical information, that I'd advocate for inclusion in our training programs.

Klinck and Clements-Cortes conclude the book by providing guidelines on using music for medical assistance in dying, funeral planning, relationship completion, and bereavement. The authors provide procedures and discuss specific goals, techniques, and ethical considerations.

"Relationship completion in palliative care music therapy" is a valuable addition to the existing literature on this topic. The book provides essential theoretical and practical information that should be included in the textbook list for music therapy training programs. In addition, its large scoping inclusion reviews music and its potential in healthcare, and offers expansive thinking for milieu team members, in addition to its potential in music therapy.

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