Practice Informed Research in Oncologic and Palliative Music Therapy: From Clinical Data-Mining to RCT

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Abstract
Practice informed research described in this article is grounded in research questions arising from the author’s work as an oncologic and palliative care music therapist for over 20 years. Constructivism offers an approach for examining varied perceptions that patients and caregivers, including the music therapist-researcher, have about music therapy phenomena. Data may be accessed through “clinical data-mining” the metaphorical mine of information contained in therapists’ routinely kept records (Epstein, 2001) and, it is suggested, prospective and retrospective clinical diaries, memories, and products (e.g., song lyrics). Mixed methods research, including a randomised controlled trial and subjective data collection, can offer varied perspectives of music therapy phenomena, meaningful to people with positivist and constructivist world views. Research projects encompassing varying models are described including, “therapist as researcher”, “therapist-researcher partnership”, “reflexive group supervision,” and a multidisciplinary research team. Music therapy knowledge can be meaningfully extended through “data-mining” the practice wisdom of experienced music therapists, and research projects focused on questions emergent from practice.

Keywords: oncology, music therapy, practice research, clinical data-mining

Introduction
In 1982-85, commencing careers in social work and music therapy in a newly established hospice, alongside a neurological hospital, was interesting. At Bethlehem Hospital in Melbourne,¹ I felt witness to a knowledge frontier. Palliative care philosophy and services were burgeoning throughout Melbourne. I finished music therapy training with Lucanne Magill at

¹ Now known as Calvary Health Care, Bethlehem

Volume 20, special issue, 2009 Australian Journal of Music Therapy
Memorial Sloan Kettering Cancer Centre (MSKCC) in New York in 1985 and, soon after, Susan Munro visited Melbourne. In 1975, Susan had created the first music therapy position in a palliative care unit, in Montreal. Their work, alongside Ruth Bright’s books on aging, grief, and loss, were inspiring. I relinquished social work and started writing about my music therapy practice to help me make sense of what I was experiencing, debrief, educate myself and others, and gain recognition for the work. Interest was widespread but extending clinical hours was challenging. “You need proof and the best evidence”, I was told, “comes from randomized controlled trials (RCTs)”. As colleagues and I could not imagine how to prove music therapy’s effectiveness using available quantitative research methods, and A/Prof Denise Grocke’s qualitative research initiatives expanded my sense of research possibilities, my practice informed research journey began. After delineating my conceptualization of practice informed research, I will briefly mention related research projects through the first 20 years of my music therapy career (1985-2004). Recent and current research projects, their paradigmatic context, and my future research imaginings will then be the focus.

**Practice Informed Research**

My practice informed research emerges from questions grounded in my daily work as a music therapist, and is intended to usefully inform that work in the future. In doing so, practice informed research reflects my agreement with Scott’s (1990) assertion that the experienced therapist’s font of practice wisdom should be harnessed to meaningfully extend a profession’s knowledge base. My practice informed research encompasses two research models already described in the social work discipline: practice-based research and research-based practice (Epstein, 2001). Practice-based research is defined as, “the use of research-inspired principles, designs and information gathering techniques within existing forms of practice to answer questions that emerge from practice in ways that inform practice” (Epstein, cited in Epstein 2001, p. 17). This is contrasted with research-based practice which is “the use of research-based concepts, theories, designs and data-gathering instruments to structure practice so that hypotheses concerning cause-effect relationships between … interventions and outcomes may be rigorously tested” (Epstein, 2001, p. 17). The contrasting emphases in these two approaches are found in Table 1. While practice-based research is the model with which I am most accustomed, my recent involvement with a randomized controlled trial (RCT) has led to my belief that both research approaches can: (a) attend to research questions that emerge from clinical

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2 Accolades to Bridgit Hogan, who later developed the program at Bethlehem Hospital into an internationally renowned and large Music Therapy Department.

*Volume 20, special issue, 2009*  *Australian Journal of Music Therapy* 17

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practice; and (b) enable research findings that can, in turn, inform and extend the quality of one’s practice.

Table 1

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<thead>
<tr>
<th>Practice-Based Research</th>
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<tr>
<td>Inductive</td>
<td>Deductive</td>
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<tr>
<td>Non-experimental or quasi-experimental designs</td>
<td>Seeks causal knowledge, prioritizes randomized control designs</td>
</tr>
<tr>
<td>Seeks descriptive or correctional knowledge</td>
<td>Uses standardized research instruments</td>
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<tr>
<td>May be retrospective or prospective Quantitative or qualitative; instruments tailored to practice needs and requirements which outweigh research considerations</td>
<td>Research requirements outweigh clinical considerations</td>
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Emergence

The first twenty years of my practice informed research will be briefly mentioned for historical context. They included: (a) “quasi” grounded theory research examining the most effective musical and communication skills used to communicate with people with significant brain impairment (O’Callaghan & Brown, 1989; O’Callaghan & Turnbull, 1987, 1988,)³; (b) modified grounded theory research projects uncovering song themes written by palliative care patients (O’Callaghan 1996), and delineating the effect of a music therapist’s introduction on oncology patients’ engagement (O’Callaghan & Colegrove, 1998); and (c) constructivist research examining varied perceptions about oncologic music therapy’s effect (O’Callaghan, 2001a, 2001b, 2004, 2005, 2007; O’Callaghan & Hiscock, 2007; O’Callaghan & McDermott, 2004, 2007). The work in brain impairment, conducted with a neuropsychologist, and the lyric analysis Masters of Music research, were inspired during my work at Bethlehem Hospital from 1982 to 1991. Oncologic music therapy work at Repatriation General Hospital Heidelberg⁴, from 1988-1997, also inspired the lyric analysis research, as well as the therapist-researcher partnership (McHart & Hess, 1995)⁵ when I

³ I later realised that neuropsychologist, Gemma Brown (Turnbull), and I had been instinctively conducting grounded theory type research here, while completing the Social Science Research Methods subject at the Royal Melbourne Institute of Technology in Melbourne in 1991.
⁴ Now Austin Health.
⁵ McHart & Hess (1995) refer to the “practitioner-researcher partnership” which reflects the social work origin of this concept. Practitioner is a descriptor widely used to depict social workers, however, therapist-researcher is arguably a more appropriate description of this research model’s application to music therapy.
supported Vivienne’s Colegrove’s inquiry into engaging oncology patients in music therapy sessions (O’Callaghan & Colegrove, 1998). The constructivist research on music therapy’s effect in oncology was inspired by my employment at Peter MacCallum Cancer Centre (Peter Mac) from 1998. Work at both Peter Mac and Caritas Christi Hospice St Vincent’s Health (since 2004) also informed my National Health and Medical Research Post Doctoral Fellowship in Palliative Care (2008-9) application, which will be explained later.

**Establishing the Gaze: A Constructivist Lens**

Edwards (1999) suggested that music therapists consider the paradigmatic frames that inform their understandings about how knowledge is created and how research can proceed. This can enable us to communicate our work in more meaningful ways to others who have different paradigmatic assumptions. My world view accommodates tenets of many paradigmatic frames which have been presented with some variation in the literature (Cresswell & Plano Clark, 2007; Fossey, Harvey, McDermott, & Davidson, 2004; Guba & Lincoln, 1994). Essentially, I accept that hypothetico-deductive research can usefully extend understanding about inanimate matter, and varying aspects of organic matter. I tentatively accept that the positivist world view can contribute to understandings about human experience, albeit mindful that positivist methodologies use measurements which reflect researchers’ beliefs about what is important to know. As positivism renders the researchers’ views as more important than the research participants’ subjective experiences, and participants’ beliefs about what researchers should know (McGrath, 2000), my allegiance is toward the qualitative methods. Qualitative approaches, in my mind, are aligned with client-centred care, that is, “starting where the client is at”, which is congruent with my clinical practice approach.

Ultimately, I am inspired by constructivism which maintains that our perceived reality is constructed by our historical, social and individual contexts (Kuper, Reeves, & Levinson, 2008). Constructivist researchers value the multiple interpretations that research participants and analytical “experts” can have about a specific research phenomenon, and support their dialectical exchange (Guba & Lincoln, 1994). Knowing about the world is “socially and experientially based, local and specific in nature” (Guba & Lincoln, 1994, p. 110) although specific elements can be shared among individuals and cultures. The investigator and object of the investigation are linked. Knowledge is developed as multiple constructions of reality are interpreted, compared, and contrasted. While early discussants of constructivism stated that the constructivist researcher aims to distil a “consensus construction” (Guba & Lincoln, 1994, p. 111), I believe that such “consensus” does not indicate searching for a single “truth” but, rather, indicates the process where
researchers (and, where possible, participants) can critically examine each other's perceptions about the researched phenomenon so that a more complex construction may result. This qualitative inter-rater reliability process is further explained by Kitto, Chesters, and Grbich (2008).

My attraction to constructivism is based on my interpretation that the paradigm can accommodate the tenets of mixed methods research design, and can consequently provide a frame for open dialogue about specific research phenomena amongst researchers with contrasting ontological allegiances, positivism and constructivism. As broad patterns of shared understanding emerge through dialectical exchange about the subjective phenomenon of music therapy experience, even across these world views, I imagine that further grounded theories (Corbin & Strauss, 2008) can develop. While my grounded theory research has only enabled substantive grounded theories (Daveson, O'Callaghan, & Grocke, 2008; O'Callaghan & Magill, in press), and has mostly encompassed textual data, I can imagine how more formal grounded theory development can encompass findings grounded in diverse understandings, including positivist, about a specific phenomenon. This is because grounded theory adheres to the principal that anything related to the researched phenomenon can be data. But these thoughts reflect current speculations and grappling with mixed method research; they may alter as time passes and further dialogue is shared.

Clinical Data-Mining

Over the past few years, my research has been inspired by the tenets of "clinical data-mining" (Epstein, 2001), which privileges the metaphorical mine of precious information often contained in a therapist's routinely kept records, and is potentially transformable into data for research purposes. While advantages and disadvantages in this approach have been discussed elsewhere (Epstein, 2001), the overriding advantage is that clinical data-mining research can extend a professional knowledge base in non-intrusive ways to clients at less cost (compared to data generating research methods), and any problems related to data quality "can be dealt with like any other applied research problem, i.e., with strategic compromise" (p. 23). Prof Irwin

6 Beliefs about knowledge have been divided into objectivist and constructivist approaches for medical research (Kuper et al., 2008).
7 Grounded theory research procedures can lead to three levels of theory development: substantive, middle range, and formal, which denote decreasing levels of specificity to a group and/or place. Grounded theory encompasses a set of well-developed codes, categories, and themes that are "systematically interrelated through statements of relationship ... that explains some phenomenon .... even though ... theory may become outdated as new knowledge comes to light" (Corbin & Strauss, 2008, p. 55). Daveson's (Daveson et al., 2008) developing indigenous theory or DIT framework also illustrates how precursors to theory, and grounded theory, can be conceptualized in music therapy.
8 Epstein (2001) refers to the "clinician" which reflects the social work and health origin of clinical data-mining. Clinician is a descriptor widely used to depict health workers, however, therapist is arguably a more appropriate descriptor when considering this research model's application to music therapy.
Epstein’s (2001) ideas and regular consultations in Melbourne have informed many local allied health research projects (Joubert & Epstein, 2005).

While engaged with Prof Epstein’s work, it occurred to me that my PhD research had encompassed a study in which I prospectively created a data mine for future analysis. I kept a clinical reflexive journal for 12 months describing my beliefs about music therapy’s relevance (what it did and whether it helped) in a cancer hospital. I then “mined” these clinical memories and reflections, using inductive thematic analysis, to present my systematically derived representation of my music therapy program’s relevance (O’Callaghan, 2005). I also discovered that the process, in itself, was a significant “self supervisory” and educative tool.

*Research from 2004: Clinical Data-Mining of One’s Previous Clinical Experience*

After considering the “data mine” analogy for this PhD study, I wondered whether I could use my clinical memories as data, and mine those memories in another research project. I questioned whether the clinical data-mining of one’s clinical memories and artifacts could also serve as a self-educative tool, while furthering music therapy knowledge, somewhat akin to “autoethnography” (Crawford, 1994) and retrospective clinical journal writing research (Mulder & Gregory, 2000).

In order to examine the viability of retrospectively data-mining one’s clinical experiences as a research method, I created two clinical research questions that I was curious about: (a) What clinical experiences elicited my conception that lullaby and lament qualities were evident in palliative care music therapy?, and (b) What was my perception of the relevance of these qualities for patients and their significant others? The “mine” of data sources included a 300 000 word clinical reflexive journal, my published academic work and post graduate theses, and further session memories and artifacts (notes, songs, etc). Grounded theory research principles were used to “excavate” this mine and a final construct emerged, the “lament”, which signified helpful musical “moments when patients’ and families’ personal and sociohistorical relationship with lullabies and laments were actualized” (p. 93). A music therapist could enable the lullament through providing opportunities for music-contextualized “restorative resounding” (O’Callaghan, 2008).

This research extended my practice through enhancing my perception about music’s power in palliative care, as well as arguably extended music therapy knowledge. The data-mining (Epstein, 2001) of one’s clinical experiences as a research process is recommended to anyone curious about a specific phenomenon in their practice. The process may be shared with another therapist, researcher, or supervisor. For example, Pip Barry questioned the appropriateness of the “predetermined” goal music therapy
practice model during in an oncology music therapy placement, which I supervised. On her placement’s conclusion, Pip analysed her clinical reflexive journal, which she had written during her placement, as well as further consequent reflections. I accompanied Pip in this research process as a qualitative inter-rater” (Kitto et al., 2008) whereby I considered some of Pip’s data interpretations with her to extend the findings’ complexity. Pip’s data-mining of her clinical reflexive journal revealed a process of learning and music therapy knowledge contribution, highlighting the need for flexibility as an oncologic music therapist, and musical environmental therapy’s (Aasgaard, 1999) relevance in an adult oncologic setting (Barry & O’Callaghan, 2008).

Clinical Data-Mining of Group Member’s Previous Clinical Experiences

In mid 2008 I was invited by Helen Petering to conduct group supervision with three music therapists at Eastern Palliative Care, Victoria, specifically about the phenomenon of unfinished music therapy legacies in palliative care. In preparing for this meeting I found many reflections about the value of palliative care patients creating legacies in the literature, but nothing on therapists’ experiences when the legacies were incomplete, because the patient deteriorated, died, or was relocated. Burnout is associated with palliative care staff not fulfilling personal expectations of themselves (Vachon, 2004) hence the examination of therapists’ experiences of patients’ incomplete work was important. I therefore considered how the principles of clinical data-mining could apply to a group of therapists describing their professional experiences.

I proposed that the three therapists, Helen Petering, Amy Thomas, and Rebecca Crappsley, and I, share a “reflexive group supervision research” process that included (a) extending all of our considerations about unfinished palliative care legacies, and (b) creating data for a clinical data-mining project to address this knowledge gap. In this research project, we would all be therapist-researchers. Reflexive group supervision was defined as a process when professional group members share clinical experiences and reflections with each other in a supportive context. Members may request clarification and provide feedback, including affirmation, alternate opinions, and invitations to consider alternate assessments and actions. The aim is to promote each others’ examination of their beliefs, theories, action, and knowledge in relation to their practices. In reflexive group supervision research, the group agrees to a framework for discussion that encompasses a research aim and method, including the delineation of data, discussion guide, and mode of analysis.

This research, with authorship shared by the four therapists, is almost completed. If successful, it is hoped that the research model, directed at
mining and harnessing experienced therapists’ clinical fonts of knowledge, will be helpful for other therapist-researchers. The research design may also be useful for therapist-academic research partnerships in order to promote “knowledge reciprocation” between clinical and academic settings. Conceivably, reflexive group supervision research may proceed with or without a group leader.

Research from 2004: Mixed Methods

I conceive my music therapy role as one that provides direct clinical services to clients, and also promotes a healthful music presence in their clinical contexts. During my work at Peter Mac some years ago, I was struck by varied contexts, both positive and negative, that some patients spontaneously made about radiotherapy experiences. As I shared stories with various radiation therapists, we realized that the ad hoc way that the radiation therapists provided music needed attention. Often patients were not invited to choose the music, which was a concern because people’s preferred music is most associated with relaxation (Stratton & Zalinowski, 1984). In 2004, there was scarcely any literature reporting music for radiotherapy. Smith and colleagues (2001) had examined the effect of restricted self-selected music on the anxiety of men receiving a series of radiation therapy treatments but the patients were given a limited choice of music genres and tapes. State and trait anxiety scores, which were measured throughout the lengthy treatment, were not significant. As the authors acknowledged that the lack of available preferred music may have influenced their results, and that early radiotherapy sessions can be the most stressful (Lamzus, Verres, & Hubener, 1994; Mose, Budischewski, Rahn, Zander-Heinz, Bormeth, & Bottcher, 2001), we decided to examine the effects of music that patients selected for themselves (brought in from home) in the first radiotherapy session. As we were interested in patients’ experiences according to the researcher devised state trait anxiety inventories, as well as what patients felt we needed to know, we developed a triangulation mixed methods convergence design (Cresswell & Plano Clark, 2007) comprising of an RCT plus subjective data collection. This means that qualitative and quantitative results are collected at the same time, and the results are then compared and contrasted, ultimately informing the final representation of the data and interpretation of the findings.

It is one thing discovering a clinical knowledge gap and what one perceives to be an important research question; it is another thing finding the

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9 Thank you Helen Petering, Amy Thomas, and Rebecca Crappsley for conceptualizing this knowledge gap and for allowing me to experience and describe our research collaboration. NB. Since this article was written the authors have heard that the unfinished legacy research was accepted for publication (O’Callaghan, Petering, Thomas, & Crappsley, in press).

10 Our original design in 2004 did not encompass the label “Triangulation Mixed Methods Design based on the Convergence Model”. Later examination of this descriptor by Cresswell et al. (2007) indicated that the label “fitted” the method we had created.
funding to realize the research imagining. In hospitals like Peter Mac, staff are encouraged to apply for research grants from the Hospital’s Foundation which are highly competitive. Following the Foundation’s rejection, A/Prof Denise Grocke, through the Faculty of Music, University of Melbourne, garnered funding and became a welcome member of our research team. This funding was then matched by Peter Mac, and the research has now collected data from almost all of the 100 anticipated participants.

Working collegially with this team of researchers,\textsuperscript{11} who collectively care about the sound space of the hospital environment and its effects on patients, has been educative, interesting, and enjoyable. The knowledge outcomes will hopefully inform radiotherapists’ sensitive consideration of the music environment during patients’ treatments, and music therapists’ conversations with cancer patients about music for self-care.

2008-9: A Post Doctoral Fellowship Provides Time to Realize Research Visions

I am currently on two years leave from my clinical work while undertaking an NHMRC Post Doctoral Fellowship in Palliative Care. The main component of this research is about examining the relevance of music in the lives of people with life threatening cancer and their companions across the lifespan. While there is much focus on professionally created and funded supportive care modalities in cancer care, there is scant examination of what people with cancer do for self care. In the one study found, music was the second most commonly used coping strategy by 292 cancer patients (43\%) after prayer (64\%) (Zaza, Sellick, & Hillier, 2005). When applying for the post doctoral funding I argued that it was important to understand more about what people are initiating to help themselves through their cancer experiences to potentially (a) inform supportive music initiatives in cancer wards and palliative care programs, and (b) offer helpful information for others going through comparable experiences. Hence, I am currently developing a series of interview studies with people living with cancer across the life span, including patients, their companions, and staff.

During the Fellowship, I have also examined two other research questions arising from my clinical practice, which I will now describe.

*Effect of Music Therapy on Staff Bystanders: A Substantive Grounded Theory*

Uncertain about the effectiveness of my newly commenced music therapy program at Peter Mac in 1998, I decided to examine its relevance in a

\textsuperscript{11} Mike Sproston, David Willis, Kate Wilkinson (radiation therapists), Dr Alvin Milner, Vicki Waleher, (statisticians), Dr Greg Wheeler (radiation oncologist), and A/Prof Denise Grocke (music therapist).
research project encompassing five studies for a PhD. A surprising finding from one of the studies involving staff was that 38 of the 61 staff who wrote about music therapy’s effect, stated that it helped themselves as bystanders. Staff had been invited to anonymously participate via a Plain Language Statement that requested written comments: “Any thoughts or feelings you have about music therapy will be relevant, including your own observations as well as reports of patients’ or visitors’ feedback”. I had expected staff to primarily focus on patients and visitors in their responses.

In 2001 Lucanne Magill also conducted interviews with 62 staff at MSKCC, asking what the effects of overhearing music therapy were on themselves. This year we conducted a grounded theory research project examining the effect of oncologic music therapy on staff bystanders. First, I “data mined” the relevant previously collected and analysed data from my PhD.12 Second, Lucanne conducted an inductive thematic and comparative analysis on her interview data. We then comparatively analysed the two studies’ data, analysis, and findings, finally uncovering a substantive grounded theory illuminating the mostly positive effect that public ward oncologic music therapy had on staff bystanders (O’Callaghan & Magill, in press). Oncology staff benefit from group support sessions (Le Blanc, Hox, Schaufeli, Taris, 2007) and complementary therapies (Wilson, Ganley, Mackereth, & Rowswell, 2007). Our research is the first to examine how oncology staff’s working environment can improve their well-being, in this case, through witnessing, and occasionally participating in, patient/visitor-centred music therapy (O’Callaghan & Magill, in press).

Analyzing Cancer Inpatients’ Music Therapy Song Lyrics for their Children

The final description of a practice informed research project is grounded in my work with parent oncology patients who wrote songs for their children in music therapy. I felt that I was conducting this work almost in a theoretical vacuum. While I worked on the basis that some of the messages in the songs were important for parents to communicate with their children, and that it seemed important for the children to have the song legacies if their parents’ died, I imagined that there was further theoretical foundation for substantiating the therapeutic potential of this method. Exploration of related literature revealed a dearth of ideas about how to help parents with serious cancer diagnoses communicate with their children (Salzinger, Cain, Porterfield, & Lohnes, 2004; Turner, Yates, Hargraves, & Hausmann, 2007). Given the profound work that I knew was occurring in

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12 In grounded theory, one can use data that has been previously analysed when it is relevant for a new research question (Corbin & Strauss, 2008). As Ethic’s approval was not required to collect this staff data (just senior Managers’) the inclusion of this retrospective data and analysis in the current grounded theory research was not an ethical problem. When considering the use of retrospective client data and analysis for a new research project, however, one would need to consult the relevant Ethic’s Committee.
music therapy between parents with cancer and their children, especially in regard to parents’ song writing, I felt it important to address this knowledge gap.

I examined lyrical ideas that patients were expressing in their songs for their children (for which I received Peter Mac’s Ethic’s approval), and then examined lyrics that other music therapists have helped oncology patients to write for their children in the public domain. Not only was I mining my own collection of music therapy artifacts, I started to mine others. Hence I invited two oncologic music therapists who have used song writing extensively, Emma O’Brien and Lucanne Magill, to help me “data-mine” the relevant songs available in the public domain (which were mostly written with their own patients) and to help with lyrical analysis, etc. A social work colleague also collaborated, providing inter-rater assistance (Elizabeth Ballinger). The lyrical research findings, alongside developmental, attachment, and bereavement theory, enabled us to conclude that the parents’ song lyrics may support their children during the parents’ illnesses and beyond. Parents can also use the song writing for personal therapeutic effect, including catharsis and for imagining their presence in their children’s lives beyond their deaths. Qualitative researchers rely on theory to “illuminate their findings” (Reeves, Albert, & Hodges, 2008, p. 631). This work will hopefully substantiate the value of music therapy in oncology for supporting parents’ and children’s communication when the parent is hospitalized with cancer (O’Callaghan, O’Brien, Magill, & Ballinger, in press).

The Future

Future research initiatives beyond my post doctoral commitments are difficult to imagine as they are affected by a complex interplay of factors, including personal, professional, organizational, and political. I expect that this post doc will be like my PhD experience, that is, provide me with a rich array of understandings about music and cancer that, alongside ongoing clinical work, will inspire reflection, dialogue, writing, and further research questions in future years. My research journey has established my confidence in, and regard for, practice informed research, and a hope that it vitally contributes to our evolving knowledge base, through varying research models such as those described in this paper: therapist as researcher, therapist-researcher partnership, reflexive group supervision, and the multidisciplinary research team.

Occasionally I dare to dream about being part of a clinical and research focused centre of medical music therapy excellence, or being part of collaborative adventures exploring experienced music therapists’ subjugated knowledge through clinical data-mining research. And then I look at the Leunig (1995) cartoon that has sat in my office for many years. It has two
pictures: in one a man enters an establishment called: "The Academy of Ancient Music"; the other picture is of birds singing in a leafy tree with the caption, "The Academy of Very Ancient Music". I am reminded to remain grounded and to try and do my best to honor the sound stories among those I meet on my privileged journey.

References


