
 Editorial

Dilemmas of Responsibility Related to Contexts of Research & Performance

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When investigators undertake research, the context of how projects are organized is critical to consider. Enthusiasm with a topic, and the subsequent detailed organization in preparing timelines for planning and instituting activities that will lead to the validating or refuting of a hypothesis, consume many hours of a researcher's time. The scientific community seeks truth that beckons for evidence that is predictable and outcomes that can be replicated.

In an environment of setting forth circumstances where a cause and effect can be controlled, the collective 'we' (meaning the community, who are interested in growing specific knowledge-bases) take pride in sharing and growing not only the understanding of phenomena, but in germinating its usefulness and influence in its application to humankind.

Research can best be understood within a context. The way information is relayed is intricately connected to several critical points of contexts. The concern of context is a backdrop that influences each and every component of a clinical trial, as it preempts a framework that we must consider seriously. I remember dining a few years ago with a colleague I respected, and as we discussed outcomes related to the work of various researchers on topics we both fancied, he surprised me. He named a researcher whose work we both knew and criticized the work and findings of this researcher's investigations mentioning that the foundation that had funded the project was not reputable. He said that the person at the top of the funding corporation had been convicted of a crime (unrelated to the project) and he insinuated that in some way, as a result of this, our mutual colleague's study was therefore tainted, and had limited value.

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It was surprising, and prompted a reminder of just how much any and all activities related to research affect perceived outcomes. The context of our mutual familiar colleague's research funding source had negatively impacted my friend's impression of the project itself, even as it had virtually nothing to do, of course, with the study itself. And even as the funding had been provided years before the corporation head had been found guilty.

If we look at the actual definition of 'context' [1]—one of its meanings is: "circumstances under which a document was created, including its function, purpose, use, time, the creator, and the recipient." Context leaves us with much to consider well beyond the content of a project. Who is funding and what is the incentive of a funder should have little to do with the research itself, but so often is viewed in terms of content and potential biases. How are co-investigators selected and what are the overt and covert expectations? How is the research question and topic decided and how long will the study take? One of the most influential, and likely most published investigators I know (who will remain nameless for the purposes of the editorial) professed to me several years ago that "when all is said and done" from start to finish projects took on average, about 10 years "at least" to complete. This was a comfort, but also a surprise, and eye opening, because I have plenty of colleagues who have pushed out studies in a few years or less, and this had always amazed me. In the land of researching a phenomenon, much is at stake in the selection of ingredients, and how they are mixed together. It is anything but simple.

Questionable topics related to research activity should be supported by good design and thorough literature review. There may be validity in repeating an investigation to confirm a hypothesis, but the literature review should be informed enough to reflect that such a case was purposeful, and not a mere waste of time.

Perhaps of even more concern and often under-addressed are citations purposefully omitted, due to investigator/authors political wars, or even firm opposition to their colleagues' ideologies. Cruelty to animals utilized in clinical trials is another scorned context of certain projects that some peer investigators do not approve of. And yet it often remains unmentioned.

In research and testing, animals are subjected to experiments that can include everything from testing new drugs to infecting with diseases, poisoning for toxicity testing, burning skin, causing brain damage, implanting electrodes into the brain, maiming, blinding, and other painful and invasive procedures. It can include protocols that cause severe suffering, such as long-term social isolation, electric shocks, withholding of food and water, or repeated breeding and separating of infants from mothers. In toxicity testing, animals used in chronic toxicity and carcinogenicity studies receive the test substance daily, seven days a week, for up to two years with no recovery periods. Many, if not most, animals die before the end of the study. With the exception of chimpanzees, animals that survive their use in research and testing can be killed after the study is completed [2].

The notion of using relevant and recent publications is a preferable premise for editors. Most people assume that current researchers that have published more recently are perhaps more on top of a topic than ones who published on a similar topic in years past. This reality is perhaps not so stringently affirmed, so much so that many lines of thinking, or investigating become lost or remain forever hidden, unless their preferred subject's content is suddenly re-opened decades later. At that point, another author may be presenting it as new and novel, and the reference may remain undervalued.

This is an unfortunate aspect of research, and largely stems from a limited literature review and/or an under-experienced investigator that may be scrutinizing a topic in a vacuum, with little involvement of peers and sparse hands-on contact with patients (clinical experience). These two aspects of knowledge may be the most essential elements of undertaking a comprehensive study.

We are clearly living in a critical age, particularly as access to information and our capacity to use so many avenues of access is exploding. With technology improving at such a rapid rate, transparency is seemingly increasingly expected, and so many aspects of contexts are under comprehensive, additional scrutiny.

When we are able to gather materials and connect with the source and function of how trials are collected and the way in which data is analyzed - whether by a team or through an 'app', whether in print, or faxed, or linked to via 'green' mechanisms rather than in print - expectancy of efficiency increases. In some ways it seems that as a result of the process of gathering and sharing information taking less time, the hyper-vigilance for all other parameters under consideration has intensified. This has made the context of findings be under seemingly greater scrutiny. Now, more than ever, the 'general public' audience, and the smaller community of 'readerships' amongst special topics are evaluating each and every aspect of research activity including the topic, the procedures, consent/s, the ethics of activity, how decisions are made, the review process, and of course full disclosure and transparency of how decisions impact outcomes and influence strategies.

One example of data gathering that is influencing the mechanisms of context in study data collection and informants can be seen in 2 large funded projects that have been running for more than 2 decades. The study population, women with cervical cancer, tracked a large group of women from poor parts of India whose cervical cancer treatment involved careful monitoring and treatment of the progression of their disease, but did not include screening them.

Of the 2 studies, the one funded by Gates (the other by the National Cancer Institute), left 76,000 women with what was thought to be inadequate information about their options for screening, and informed consent, according to the Office of Human Research Protection, part of the U.S. Department of Health and Human Services, was also not obtained adequately.

The Gates Foundation research has approximately 31,000 women who were not routinely screened or treated for cervical cancer. There have been ethical concerns related to both the Gates and NCI study about the numbers of women from the 'controls' who, although their care for the cancer was free of charge, their screenings were not mentioned or part of the advisement. The many women placed in "control groups" who were offered free visits with health-care workers, were not provided with access to be screened for cervical cancer.

The research tabulated the death rates of women screened and treated for free, and as the data showed beneficial outcomes as a result of screening, the thinking was that the women in the control groups should have been shifted immediately to the screening option group. The NCI study sought to view the efficacy of a diluted acetic acid (vinegar) to a woman's cervix, in assessing color changes (abnormal tissue will temporarily turn white) [3].

Another dilemma uncovered through outside scrutiny was that it was not certain "how many of them fully understood. Very few acted on their own to seek screening" - even as consent was obtained through explanation and signature [4]. This not an unusual problem related to research conducted in countries that have poverty, where subjects include minority populations who have not been exposed to any kind of self-advocacy. How can we deny those most in need of intervention with controls, and, even in weight-listed controls in many diseases, time for inclusion is of central essence in consideration of the disease process. The context of time and the value of its relevance in judging whether a finding is indeed 'current' and then, the particular of *how* it is judged and its relevance to humanity are often on the minds of investigators and reviewers.

How a sore topic from generations past (such as elders who have committed war crimes more than a century ago) is considered in the modern world is one context to ponder in terms of morality, justice and the law, but another perhaps even more difficult task to reckon with is whether a topic should be considered appropriate to study and/or publish at all.

This question was certainly begged last summer when in NYC amid intense picketing and criticism of the Metropolitan Opera over a work about the murder of Jewish cruise ship passenger, Leon Klinghoffer. The show went on regardless. ‘The Death of Klinghoffer’ composed by John Adams faced much scrutiny and the screen production of it typically provided through the Mets circulation was cancelled. The subject of this work was the hijacking of an Italian cruise ship Achille Lauro by Palestinian terrorists, and the murder of a Jewish passenger, Leon Klinghoffer, that took place in 1985. While prospective viewers presented their angst that the dramatization itself of terrorism condoned it, those involved in the writing and production related to performing it thought that it sent a larger message about the violence—one that might prompt people to be introspective about its effects on humanity, from ancient times to the modern age.

In response to the cancellation of the movie’s circulation of the piece, and upon further reflecting about how the opera may have been presented more wisely, its composer Adams said he “wished the Met had imitated the Opera Theater of St. Louis, which, before it presented the opera in 2011, held interfaith discussions on the work and its themes to educate the community.” The director of the Met, Peter Gelb’s response “that he was not sure that such an approach could work in a city the size of New York, but that he continues to speak with Jewish leaders, and might set up some discussions” [5].

In a perfect world, people involved in directing productions likely do not want to necessarily be charged with sensitivity meetings related to how a piece of music or art will or will not be accepted by a community. Is not the purpose of music and thematic productions to move people to think beyond the borders of what is comfortable, particularly in a time where conflict is escalating and world suspicion and paranoia is rising? How can we censor metaphor depicting a staged incident that might move many to own the greatest shames amongst humanity? When the opera opened in 1991 in Brussels Belgium, a review [6] said it “deliberately cools passions into meditations from afar.”

The level of trust 20 years ago did not carry such an easy interpretation last summer in the weeks preceding its delivery at the Met. One has to consider the influence of time, context and elements of trust or lack thereof in taking to understand how a piece of art can symbolize or misconstrue messaging, and as important is the consideration that the apparent threat that can be rippled across a works pre-emptive expression, including the design and production of a performance.

Had this production been performed in another century, perhaps there would have been much less eye-brow raising, and the focus would have been likely on the finale, the tragic aria at the end of the work, sung by Mrs. Klinghoffer. The context of how we create, produce and release topics is often what is at play, and our capacity to be sensitive and inclusive applies not only to art, but also to how we set out to investigate illnesses.

When involving peers, particularly those who can provide invaluable, insight is certainly easier to obtain than it was 20 years ago. We can gather answers to questions that will provide for stronger mechanisms in our data collection. We can have research meetings over the web. How often have we sent an e-mail to a colleague who has undertaken a project related to one we are about to begin, to say: “In your study, I noticed that you did not include (such and such), and was wondering why?” Not often enough. At the same time, our measurements of evaluation will likely include assessment points that involve non-music and non-medical parameters, such as speech, for instance. In such cases, a speech therapist should best be involved to be included in the context of each and every other point of evaluation that relates to language, expression, cognition etc. This is one mere example of inclusion integration.

Awareness of context implies that we are sensitive to matters involving history, and treatment of specific populations, such as caregivers. In a broader sense, we need to be aware of timing, and how the effect an intervention has could be imposing to our subjects, or might at the same time be depriving them of something that would otherwise enhance their experience either physiologically or perceptually (as in traumatic experiencing related to treatment process).

Collectively, viewing the definitions of context, and how we set up, design, invite, collect and ensue in pursuit of more effective treatment of others in our world of music and medicine projects, we should consider the background, environment, framework, setting, or situation surrounding an event or occurrence. As well, the second definition of context—the words and sentences that occur before or after a word or sentence and imbue it with a particular meaning [7], will show our integrity as authors, reviewers and consultants most intricately involved with strengthening the care of patients. And thirdly; the circumstances under which a document was (is) created, including its function, purpose, use, time, the creator, and the recipient [8], will enable us to be sensitive to the community and the humanness involved in the study of music and medicine.

In this issue, ‘The Sound of Deafness: Smetana and Traumatic Tinnitus’ Peter Pesic takes us back to the time of Bedrich Smetana’s deafness and how it affected his composing and the sonic phenomena that accompanied his loss of hearing. The physiological aspects of trauma can shape the impact of disease and music’s place within this realm should not be underestimated.

In ‘The Effects of Functionally Oriented Music Therapy on Body function and Quality of Life in Chronic Stroke Survivors and on Patients with Parkinson’s Disease’ Åsa Rosin, Margareta Ericsson, Karina Larsson consider the effects of a 20 week Functional oriented Music Therapy (FMT) program in patients with chronic stroke and in patients with Parkinson’s disease. Their data includes the collection of 15 different body-functions, and quality of life parameter that were evaluated during multiple sessions within a 10-week

follow-up period. It is novel to consider a new approach with these fragile and increasing populations.

‘The Effects Of Music Therapy Intervention In Pediatric Intensive Care Unit as Measured By The Test Comfort Behavior Scale’ a doctor and music therapist Pilar Carrasco Marina and Maria Jesus del Olmo Barros considered the level of wellbeing observed in the changes measured at two points, before and after interaction with adults in their visits to the PICU, in both conditions with and without music.

The original Comfort Scale has formerly measured the distress of children in pediatric intensive care units with mechanical ventilation. The authors’ concept of comfort sits well in this study as it is inclusive of anxiety, agitation, and pain –mechanisms often forgotten in the treatment of infants and young children.

In an under-investigated topic, Ellis Cerrone and Thomas Carroll provide a detailed look at head pain related to practice in ‘Chiari Malformation: A Potential Cause of Headaches in Brass Players.’ This interesting case study moves us to consider the causal relationship that can exist between intracranial pressure and Valsalva manoeuvres. Wind players and those who treat brass and woodwind players should take special note.

And finally, Triona McCaffrey’s, ‘Music Therapy’s Development in Mental Healthcare: A Historical Consideration of Early Ideas and Intersecting Agents’ provides an in-depth review and subsequent informed speculation on the role of healing in music and the unique advances that music therapy has made in progressing integrative medicine, particularly in the field of mental health. McCaffrey’s challenge to us that terms relating to ‘soul’ or ‘sprit’ are lost in translation, and how such interests may be taking manifestation in other terminologies that pertain to different theoretical schools of thought prompts theoretical thinking about the connection of the mind to the body. The realization that the properties of spirit may be best

encapsulated in music, but the challenge that the question of how we view the ‘self’ is ever changing, requires more rigorous thought and discussions of this kind. McCaffrey’s historical view of the language of music therapy development is well appreciated.

Finally, Helen Shoemark addresses in ‘Culturally Transformed Music Therapy in the Perinatal and Paediatric Neonatal Intensive Care Unit: An International Report’ the culture of music in medical settings by providing an international report on music therapy for infants and families in hospitals. In her inquisitive and inclusive quest to validate the significance of culture in this work, she assists readers in understanding the current priorities as we continue to meet the challenges in growing successful music therapy in neonatal and infant hospital care globally.

As always, we welcome your contributions to ‘Music and Medicine’ and there are a variety of ways to participate. Book Reviews, Case Studies, Special Reports and Full-length articles provide a variety of options, all of which extend and enhance our knowledge base and sharing of information. We look forward to your submissions.

References

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