

MUSIC, DEMENTIA AND THE ORGANIZATION OF KNOWLEDGE

MÚSICA, DEMÊNCIA E A ORGANIZAÇÃO DE CONHECIMENTO

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ABSTRACT

Introduction: The field of knowledge organization can assist caregivers of people with dementia. But to do this, we must adjust our theories and principles of classification.

Objective: The study described below seeks to understand, from a knowledge organization perspective, how music serves to lend order and coherence to persons whose cognition has been compromised. **Methodology:** This article will show the results of interviews with caregivers, along with evidence from previously published memoirs.

Results: By analyzing this data according to theories of the acoustic aspects of music, we can see that the classification of information is not fixed in the way we encounter it in libraries. **Conclusions:** In dementia care, knowledge relationships emerge gradually from the interactions between the caregiver and the person with dementia, through repeated ritual activities.

Descriptors: Dementia music. Knowledge organization. Communication.

1 INTRODUCTION

As we move into the third decade of the twenty-first century, the principles of knowledge organization (KO) are gathering fresh relevance, and facing fresh challenges. In a world of rapid and wide communication, fake news and information overload, our need for what Elin Jacob describes as “cognitive scaffolding” (JACOB, 2004, p. 515) — the use and widespread adoption of taxonomic classifications that facilitate information retrieval, comprehension and use—has never been greater. At the same time, growing numbers of people across the world are caring for family members who suffer from cognitive deficits in the form of dementia. More and more of us are acting as intermediaries

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between a relative with dementia and a world that the relative can no longer comprehend. In this sense, family caregivers are no longer merely users of knowledge organization tools; we have become knowledge organization tools, embodying in our behaviour, words and interactions the cognitive scaffolding necessary to maintain loving relationships. How, then, can we adapt the principles and concerns of knowledge organization—classification, vocabulary control, deployment of taxonomic and associative relationships, domain analysis and principles of warrant—to the needs of people caring for family members with dementia?

As with many dementia research projects, this one begins in direct experience; it arose initially from close observation of my mother, who developed Alzheimer's Disease, and my father, who developed vascular dementia following heart surgery. Over the ten years of their illness, while conducting volunteer music sessions in long-term care facilities, I observed a curious phenomenon. Residents with advanced dementia who could not speak, could sing, and this ability appeared to surprise them as much as it did me. The study described below seeks to understand, from a knowledge organization perspective, how music serves to lend order and coherence to persons whose cognition has been compromised. It seeks, also, to find ways in which that effect can be replicated in non-musical settings to improve the interaction between persons with dementia and their family members. By combining the insights of personal caregivers, gleaned from qualitative interviews and published memoirs, combined with insights from the literature in cognitive science, nursing and neuroscience, the study aims to apply knowledge organization principles to the alleviation of caregiver stress, the enhancement of emotional connection, and the preservation of loving relationships for as long as possible.

2 BACKGROUND

The statistics are frightening:

The number of people with dementia in the Americas will nearly double ever 20 years, increasing to 14.8 million in 2030, and 27.1 million by 2050. However, rates of increase through to 2050 will be much more rapid for Latin

America and the Caribbean, than for North America. Thus, by 2030 numbers of people with dementia in Latin America and the Caribbean (7.6 million) would have overtaken those in North America (7.1 million), while by 2050 there would be 16.0 million people with dementia in Latin America and the Caribbean compared with 11.0 million in North America (DEMENTIA IN THE AMERICAS, 2013, p. 11).

Clearly, dementia will represent a significant global challenge in the coming decades, as these growing numbers place increasing strain on both families and national health infrastructures. For this reason, many countries are developing “National Strategies” to meet the challenge. A national strategy is a formal combination of laws, norms and policies constructed as a response to a specific challenge. Typically, a national dementia strategy addresses many aspects of dementia, including:

- Research: learning more about the various causes of dementia and developing improved methods of prevention, diagnosis and treatment (HOFMANN-APITUS, 2015);
- Technology: deploying sensor data, algorithms, predictive analytics and information visualization to design smart homes and intelligent communities that compensate for the confusion and disorientation of the resident (ORPWOOD *et al.*, 2005; ASTELL *et al.*, 2009; BLYTHE; DEARDEN, 2009);
- Care: developing systems that integrate the care provided by both families and institutions, thereby ensuring that individuals with dementia can live in their own homes as long as possible, while having access to long-term care when it becomes necessary;
- Support: expanding systems of support for alleviating the stress of families.

Argentina launched its first national dementia strategy in 2016 (Alzheimer’s Disease International 2016); Canada unveiled its first plan in 2019 (Public Health Agency of Canada 2019); Brazil is actively working towards its own plan (ENGEDAL; LAKS, 2016).

Professional information services such as libraries are currently defining an important role for themselves in these strategies. They disseminate the

growing quantities of data and knowledge about dementia, and they provide physical spaces and programming for support groups (KRASHEN, 2010, p. 42). While these two functions are useful and important, we have much more to do in the field of knowledge organization. Dementia represents a significant challenge in our field, a challenge with multiple facets:

- **Diagnosis:** there are many causes of dementia, and many types, such as Alzheimer's disease, Lewy body dementia, vascular and fronto-temporal dementia. There are also many different symptoms: speech disturbances, loss of recent or semantic memory, or changes in personality. The classification of these different types and symptoms is very difficult, and researchers often resort to the vague term, "DAT": Dementia of the Alzheimer's Type (see DONE; GALE, 1997 for a typical example of this usage).
- **Behaviour:** Support workers in long-term care facilities frequently encounter challenging behaviours: hostility, violence, fear, erratic movements, shouting, exit-seeking or complaining. These workers frequently use a classification to diagnose the causes of these behaviours: physical, medical, environmental or social (BOURGEOIS, 2002, p. 132; CAMPBELL, 2014, p. 121).
- **Categorization:** Many elderly persons with dementia exhibit changes in the formation of associations, changes occurring as the brain improvises and adapts to the confusion that develops throughout the progress of the illness. These changes frequently involve shifts in the person's capacity for taxonomic and associative connections. (AU *et al.*, 2003; MIRMAN *et al.* 2017; LANDRIGAN; MIRMAN, 2018). In the initial phase, a person with dementia might associate a carrot with another vegetable, such as broccoli or lettuce. In the intermediary phase, the person might use a cultural image, and associate a carrot with a rabbit. In the final phase, the person might respond simply to similarities of form, and associate the carrot with a rocket ship. These changes cause many problems in communication.
- **Normal/Abnormal:** Above all, the discourse surrounding dementia sustains, and depends on, a distinction between two concepts: "normal"

and “abnormal.” We all age; we all forget names and events; we all ask ourselves from time to time, “Where are my keys?” or “Why did I enter this room?” Nonetheless, physicians, researchers and care providers insist: “Dementia is not a characteristic of normal aging” (WEILL INSTITUTE, n.d.). This line between “normal” and “abnormal” is difficult to define, but this distinction—this classification—carries many profound implications for treatment, care and the formation of policies and national strategies.

While national strategies and broad policy initiatives are crucial, they will not be effective unless they meliorate conditions at the level of individual caregivers. We need, therefore, to understand these problems of organization, also, in more intimate contexts. Caregivers wish to understand the behaviour of their loved ones, satisfy their needs, and preserve good relationships as well as possible. Research in communication emphasizes the challenges in maintaining such communication in dementia settings (HOPPER, 2001; HAAK, 2002). The research described below concentrates upon the knowledge organization aspects of this intimate context, aiming to understand the problems of communication and classification that present themselves to those who care for family members with dementia, and how concepts of knowledge organization can be usefully adapted to alleviate these problems.

3 THE STUDY

This piece draws on an ongoing exploratory qualitative study, based on the following sources of data:

- Published biographies: a study of three memoirs of dementia care written in Canada between the years 2009 and 2018:
 - *Enter Mourning: A Memoir on Death, Dementia, & Coming Home*, by Heather Menzies;
 - *The Long Hello: Memory, My Mother, and Me* by Cathie Borrie;
 - *Be With: Letters to a Caregiver*, by Mike Barnes.
- Qualitative, open-ended interviews with family members caring for a person (or persons) with dementia;

- Publicly-mounted YouTube videos of persons with dementia

4 FINDINGS

The project's findings have revealed that communication constitutes a significant portion of the problems that family caregivers face. Paul Grice's study of conversational implicature has shown us that conversational interaction depends on a number of implied expectations. We expect the person we are conversing with to provide an adequate quantity of information and neither more nor less; we expect the information to be truthful and relevant, and contributed with reasonable clarity (GRICE, 1989, p. 28). Caregivers in the interview and the biographies reported that these expectations were continually frustrated. Furthermore, they expressed pain at the loss of intimate knowledge in conversations, and the opportunity to recount the events of their day to a family member who could understand and respond with sympathy and compassion. Analysis of the interviews and the memoirs revealed three recurring themes in particular: ritual, absence, and time.

4.1 TIME

In January 2017, Joe Daley, a resident of Dublin, Ohio posted a video on YouTube: the sixth in a series chronicling his experience caring for his mother, suffering from Lewy Body dementia. During that video, the mother fails to recognize him for the first time: an experience he describes as "the worst day of my life. [I heard] the words that no child ever wants to hear" (2017).

For Daley, and undoubtedly for many caregivers, the loved one's failure to recognize them feels like a permanent and catastrophic loss. The research, however, suggests a different, more complex scenario. Recent pharmaceutical experiments have raised a distinction between memory retrieval and memory consolidation (BALDUCCI; FORLONI, 2014), and recent experiments in engram reactivation in mice have suggested that memories assumed to be permanently lost could be revived (SHRESTHA; KLANN, 2016). In practical terms, caregivers can never be sure that memories are permanently lost. Dr. Anthony Komaroff,

writing for the *Harvard Health Letter*, suggests that problems of loss and problems of access are two different things:

Until recently, scientists assumed that memories lost because of dementia were permanently lost. Yet there was reason to question that, because memory loss can be fitful. Like me, you may have seen people with Alzheimer's disease who forget the name of their child until one afternoon, the name is there again. And, like me, maybe you've thought that the memories may not be permanently lost. Perhaps they're just buried deeper and are harder to access (KOMAROFF, 2019).

The memoirs by Menzies, Borrie and Barnes (2018, p. 34), as well as many of the interview participants, expressed visceral awareness of the progress of dementia: the irreversible process that Barnes characterizes as a long process of “retreat under fire” (2018, p. 34). At the same time, the experiences they describe testify to the fitfulness of individual memories. The caregivers often describe confusion, rather than emptiness: states in which memories, particularly distant memories, recur, but without any secure sense of time or chronology.

One caregiver interviewed, Victor, for instance, mentioned that his father, who was living in an assisted care facility, frequently uttered a desire to return home. He was worried and agitated, thinking about the maintenance and repair of the house; but it became gradually clear that he spoke at certain moments of his recent home, and in others, of the home of his infancy. Borrie's account of caring for her mother moves back and forth in time, as both she and her mother cautiously circle painful memories of Borrie's brother, who died many years earlier. The information from caregivers suggests that memories persist, but one of our key ordering facets—chronology—has become impaired, preventing them from ordering their memories with precision. The present and the past become intermingled.

4.2 ABSENCE

Despite the evidence of retained memories, the progress of dementia is irreversible, and all of the caregivers spoke of the gradual disappearance of the family member. One participant, Ben, described his mother's dementia as a loss

of identity: “she lost a whole lot of what used to make up her.” Victor, described his father’s condition as a loss of initiative and interest: “we’ve brought numerous things in for him and leave for him to do, and they don’t happen. [Formerly] he would never leave things to be done like that. He would assume the responsibility.” At some moments in the interview, particularly when recalling times of fatigue and sadness, the caregivers would express the perception that the object of care was no longer there, and they were caring only for what remained of their loved one without the personality—merely the physical body. At other times, paradoxically and seemingly without noticing, they insisted that the person was still “there,” often in the context of humour. Ben spoke of his mother’s “gentle sense of humour” that appealed to the nurses in her long-term care facility. Tina referred to her mother’s “dark humor,” and George referred to his mother’s strength, and the courage with which she would smile and laugh.

In negotiating this tension between presence and absence, the caregivers were engaged in a constant act of interpretation: observing carefully the enigmatic responses of the person with dementia, filling in gaps, and inferring intentions. From a knowledge organization perspective, they found themselves functioning, not from an ontological perspective but an epistemological one: dealing not with “known phenomena” that preserve their essence “independently from the means by which we know them,” but with intuitive guesses about how the other is seeing the world and interacting with it (GNOLI, 2006, p. 139). In so doing, they frequently resorted to practices which I describe as “ritual.”

4.3 RITUAL

In *The Long Hello*, Cathie Borrie describes watching birds with her mother: Every day I sit with my mother and watch the sea. There’s a row of birds perched on an errant log—cormorant, cormorant, seagull, heron. Crow.

...

“What are they trying to say?”

“To say ...? I don’t know.”

“I think there’s something, they’re trying to get something across, aren’t they, love?” (BORRIE, 2015, p. 2)

Heather Menzies describes a similar activity, this time making tea with her mother:

We always had tea, and always side by side on her bed. If it was afternoon, we looked out the window at the river and the large park in front of it, the geese stalking the lawn, the squirrels chasing each other through the trees. ...

It felt good to just be there with Mum in her room, to settle into our tea ritual. She sat on her side of the bed and I on mine, next to the wall. ... Time flowed in and out with our breathing, like the ebb and flow of the tide. (MENZIES, 2009, 103-106).

Interview participants often described similar recurrent activities. George spoke of putting on music and dancing with his mother in the kitchen. Ben spoke of a family friend who visited every Thursday with a magazine, staying for exactly the same amount of time each visit. The regularity and frequency of these shared activities appears to have served the same function as mnemonic structures in classification schemes: recurring patterns of order in a potentially confusing world, providing local stability and assurance. Mike Barnes takes the image further, to describe the entire caregiving experience as a dance of rhythmic, repeated steps: “Caregiving performs every day this two-step of the possible: what is—*what should be*—can’t be—*must be*” (BARNES, 2018, p. 40).

Evidence of the study, therefore, suggests that communication problems in dementia care arise not from a steady, predictable process of forgetting. Rather, the problems arise from an increasing dissonance between the epistemological structures of the person with dementia and those of the person providing care. As the effects of dementia force the care recipient to reroute connections in the brain to compensate for forgotten words and confused timelines, the care provider becomes an intermediary, constantly performing what Wilfrid Lancaster once described as the process of indexing: analyzing discourse and translating that analysis into the language of the system (Lancaster 1986). In the process of doing so, the repeated, rhythmic activities of ritual stood out as moments in which the communication between caregiver and care recipient was most stable and satisfying.

Knowledge organization has a role to play in the alleviation of these

communication difficulties, both as a field of study and as a suite of acquired professional skills. But the nature of that role is difficult to specify. Formal systems such as the Decimal Classification of Dewey or the Library of Congress Subject Headings typically assume the voice of societal consensus, however tenuous that assumption might be; they represent the structures that exist in the “outside world.” But what of the complex and shifting structures that take place in dementia care? How can knowledge organization find a way to play a part? In search of the answer to this question, I turned to music.

5 MUSIC

In 2014, Michael Rossatto-Bennett released a documentary that provides impressive confirmation of what many caregivers already know through experience. *Alive Inside* tells of a social worker, Dan Cohen, who used music to stimulate the memories of people living with dementia. Using iPods, he prepared playlists of music for each person, lists compiled of music that the person had enjoyed in the past. When he placed the headphones on the persons, they quickly responded. One man who had not spoken for a long time began to sing, and later to speak of the music and the love that he felt for it. A woman began to dance immediately upon hearing the music of the Beach Boys which she had loved in adolescence (ROSSATTO-BENNETT, 2014).

The success of this documentary, together with the popularity of inter-generational choirs that link people with dementia with younger singers, has brought the therapeutic effects of music to wide public attention. These effects are confirmed by numerous studies of music therapy and of retained musical abilities (ALBUQUERQUE, *et al.*, 2012). Interesting as this evidence might be, I wanted to go deeper, and consider the significance of music, not as a catalyst of memory, but as a means of understanding the stimulation of conversation in dementia care settings. How does music help to reestablish the understanding and comprehension between two people, even in a state of nearly-total confusion? This question led me to follow the lead of James Duff Brown’s Subject Classification (Beghtol 2016), and to consider music, not as a work of art, but as a form of acoustics. Acoustically, music connects to an understanding of

communication in dementia care settings by providing three powerful metaphors: tone, resonance and harmonics.

5.1 TONE

In acoustic terms, audible music is a sound: a vibration in the air and upon the eardrum. A musical tone, however, is different from other sounds, in that it is both rhythmic and repetitive. Creation of a sustained musical tone requires a vibration between two stable anchoring points. When we pluck a guitar string, for example, or draw a bow across the string of a violin or a cello, the string vibrates regularly between two stable and fixed points on the instrument (Powell 2010).

5.2 RESONANCE

The tone produced by a vibration resonates off a congenial surface, such as the wooden body of a violin or guitar. This surface, known as the “driven system,” can amplify the sound considerably, if driven at an appropriate frequency (Hartmann 2013, 23).

5.3 HARMONICS

The tone produced by the vibration, particularly the vibration of a string or a reed, contains various components known as “harmonics” or “overtones.” These harmonics occur at an integer multiple of the base frequency (Hartmann 2013, 71). We rarely hear these harmonics specifically, but they give to the tone an additional exuberance and resonance.

These three metaphors can be usefully applied to the activities of knowledge organization. The professional practices of classification and vocabulary control seek, among other things, to establish firm and reliable relationships between data and metadata, between term and concept, and among the various academic disciplines: relationships that can facilitate information retrieval and use. Whether we use Dewey’s adaptation of Francis Bacon in his ordering of the main classes, Ranganathan’s facet orders, or Farradane’s matrix of relationships, we seek to establish connections of some

reliability and utility.

Furthermore, knowledge organization systems seek the resonance of utility and applicability. Whether we in knowledge organization applaud Cutter's appeal to "the public's habitual way of looking at things" (Cutter 1904, 8) or warn against misuse of what Olson calls "the power to name" (2001, 639), we are aware that the relationships established in our systems have the potential to resonate outward and amplify assumptions and beliefs.

Above all, our taxonomic structures of knowledge aim for effects closely resembling harmonics; concepts ideally nest within broader concepts, in ways which strengthen the integrity of the "scaffolding," rather than detracting from it.

Evidence from the memoirs, interviews and videos suggests that the metaphors also apply to dementia care settings. When we communicate with persons with dementia, we too need a connection between two fixed and stable points. The caregiver must be calm, and not bring the preoccupations and stresses of living in the world into the room. The person with dementia, also, needs to be calm, which requires the caregiver to discern and, as far as possible, alleviate any anxiety the person might be feeling.

Caregiving also requires use of materials that provide cognitive resonance: photographs, videos, physical objects that trigger memories and associations.

As for harmonics, Joe Daley's YouTube video dramatically reveals the grief of caregiving: particularly the moment when the loved one fails to recognize the family member. At the same time, it also demonstrates a brighter side that Daley, at the time, could not see. While the mother, in the video, is unable to recognize him specifically, the tenderness in her voice, and the gentleness of her hand upon his arm, suggest that on some level, or some "frequency," she recognizes him as someone dear and valued. Dementia care, it seems, involves finding a pulse of interaction that is harmonious with the base frequency, just as taxonomic relationships, when properly designed, nest together harmoniously.

6 CONCLUSION

To conclude this paper on a personal note: when I visited my mother in the nursing home where she lived, I frequently sensed that upon seeing me, she in

truth saw three people: my father, whom I closely resemble; her own father who, like me, played the violin; and my own self, when she heard my voice. Cognitive scientists and neurologists might well consider this confusion a failure of categorization. But as a theorist of classification, I ask myself: is this really a failure? We all carry our ancestors in our faces and voices and characters. These traces resemble the harmonics in music. Perhaps people with dementia see more than we do: more nuances, more categories and their divisions; and perhaps the traditional categories carry less importance.

This connection between music and dementia is delicate and perhaps limited. Nonetheless, I believe that music helps us to understand the caregiving process as an act of knowledge organization, in which the caregiver acts out the task of mediating between the caregiver and the outer world. And in so doing, caregivers offer a startling new perspective on the act of knowledge organization: one based not on “scaffolding” but on “oscillation.” The conditions in dementia care are constantly changing from day to day, and no solution, no classification, no scaffolding serves us permanently. And of all the oscillations that take place in caregiving, the most important may be the distinction between “normal” and “abnormal” in the organization of knowledge in the context of dementia.

There is a time to treat dementia as an abnormal condition: to diagnose the condition, find a remedy and prescribe a treatment. But there is also a time to abandon that perspective. Descartes tells us that there is a distinction between the mind and the body: “I think, therefore I am.” This distinction leads us to consider illnesses of the mind as different, and frequently more terrifying, than illnesses of the body. But all illnesses, of mind and body, signify a universal truth: that health and life are finite for us all.

Caregivers of persons with dementia live in the tension between the normal and the abnormal. When they connect with medical systems and infrastructures—diagnoses, prescriptions, instructions, bureaucratic care systems—they live in the world of the “abnormal.” When they bear witness to an independent and strong individual gradually becoming weak and vulnerable, they live in the realm of the “normal” and the “universal.” In the future, we may find a cure for this “abnormal” condition of dementia, but nearly all of us will grow old,

and all of us will die. This fact is “normal,” and caregivers live with this fact every day.

And music? Music occupies a zone of intersection between caregivers and their loved ones. It does not cure dementia, but it can alter the quality of life. Music partakes of both the normal and the abnormal, and affects the mind and the body. Descartes says “I think; therefore I am.” Caregivers must consider an alternative phrase: “I sing; therefore I live.”

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MÚSICA, DEMÊNCIA E A ORGANIZAÇÃO DE CONHECIMENTO

RESUMO

Introdução: O campo de organização de conhecimento pode ajudar os cuidadores de pessoas com demência, para isso, temos que ajustar teorias e princípios de classificação. **Objetivos:** Busca-se compreender na perceptiva da organização do conhecimento como a música pode auxiliar pessoas que a capacidade cognitiva foi comprometida. **Metodologia:** Por meio de entrevistas com cuidadores e evidências de memórias previamente publicadas e perspectiva da organização do conhecimento fundamentam o estudo. **Resultados:** Ao analisar essas informações pela teoria de acústica aplicada à música, vê-se que a classificação da informação não é fixa como encontramos numa biblioteca. **Conclusões:** Com base a trajetória do estudo percebe-se que as relações de conhecimento emergem gradualmente da interação entre o cuidador e a pessoa com demência através de rituais repetidos.

Descritores: Demência. Organização de conhecimento. Música. Comunicação.

MÚSICA, DEMENCIA Y ORGANIZACIÓN DEL CONOCIMIENTO

RESUMEN

Introducción: El campo de la organización del conocimiento puede ayudar a los cuidadores de personas con demencia. Pero para hacer esto, debemos ajustar nuestras teorías y principios de clasificación. **Objetivo:** El estudio que se describe a continuación busca comprender, desde una perspectiva de organización del conocimiento, cómo la

música sirve para dar orden y coherencia a personas cuya cognición se ha visto comprometida. **Metodología:** Este artículo mostrará los resultados de las entrevistas con los cuidadores, junto con la evidencia de memorias publicadas anteriormente. **Resultados:** Al analizar estos datos de acuerdo con las teorías de los aspectos acústicos de la música, podemos ver que la clasificación de la información no es fija en la forma en que la encontramos en las bibliotecas. **Conclusiones:** En el cuidado de la demencia, las relaciones de conocimiento surgen gradualmente de las interacciones entre el cuidador y la persona con demencia, a través de actividades rituales repetidas.

Descriptores: Demencia. Musica. Organización del conocimiento. Comunicación.

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