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Carolyn Halpin-Healy

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FROM THE GUEST EDITORS

Well-Chosen Objects Support Well-Being for People with Dementia and Their Care Partners

Carolyn Halpin-Healy

ABSTRACT
Arts & Minds programs aim to promote well-being for people with dementia and their care partners. Educators must balance the needs of participants with the given conditions of display in the museum. While connection to the art historical canon is a consideration for program planning, the choice of artworks for contemplation and dialogue ultimately is contingent upon intersecting criteria that also take into account symptoms of dementia, accessibility, participant interests and the inherent qualities of the art object.

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> When you are with a group of people and you are looking at art and people are there to learn and to be open … you're in a space where you're joyfully looking past limits.
> – 51-year-old participant with young onset dementia, Arts & Minds at the Metropolitan Museum of Art. (2016)
> I now see the world a little bit differently through the art that we see.
> – 70 –year-old participant caregiver, Arts & Minds at the Studio Museum in Harlem. (2014)

Each week, a select team of museum educators and teaching artists prepares Arts & Minds programs for people with dementia and their care partners across five museums in New York City. Our aim is to create experiences with art that inspire comments like these above; comments that reflect participant experiences that hold art and the human dimensions of collective looking side-by-side. How do we plan for encounters that will offer the possibility for all participants, individuals with dementia and those who care for them, to look and learn, share their responses and exchange ideas in safety despite the challenges of living with cognitive impairment?[1] How can we co-create experiences that spark hope and joy?

Arts & Minds is a not-for-profit organization that partners with museums to improve well-being for people with dementia and their care partners through meaningful engagement with art. We offer direct service programs at partner museums and also provide training to assist other museums to launch and sustain programs independently. Co-founded by a museum educator and a practicing physician, the work of the organization draws on expertise in art and art history, neurology, public health, education and social work.[2] The organization is committed to improving access to cultural resources and to making museums more dementia friendly. While our roots are in art museums, we also work with museums focused on history or religious culture and we are exploring approaches suitable for technology museums and natural history collections. Our

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interdisciplinary stance holds the needs of participants and the object of our inquiry, what critical education theorist Paolo Friere calls "the epistemological object," together at the center of our work.[3] We find the epistemological object in museums – works in the art historical canon or the canon of an individual museum, which are important for critical, historical or aesthetic reasons may be as important to people with dementia and their care partners as they are to all others. Our task is to make them accessible in order to include everyone in the cultural conversation. The canonical works of any collection provide a well-defined and familiar foundation upon which to build programs. That said, there are nevertheless practical concerns related to symptoms of dementia and methods of display that may at times make canonical objects inappropriate for this audience. With regard to museum accessibility and actual or perceived barriers, it is important to note that individuals with dementia and their families may preemptively exclude themselves from cultural life, or may actually be excluded by museums, because of fear and stigma associated with cognitive impairment. In this context, the very fact that an object is situated within the canon and therefore deemed by the museum to be important, makes it important in turn to individuals with dementia and their care partners. While this holds true for all kinds of museums, here I focus on our work in art museums, primarily at The Studio Museum in Harlem.

Knowledge of art and art history is at the foundation of Arts & Minds and a passion for the subject drives our work, standing right alongside our mission to improve well-being for people with dementia and their care partners. We have consciously chosen to work in museums, rather than exclusively in elder care settings, in order to invite people who frequently live in isolation to enjoy the potentially restorative, even uplifting environment of the museum and to remain thereby in touch with the wider world of art and ideas embodied in the canonical objects of a collection. Contact with art, and all that unfolds in a collective encounter, has the potential to lead the individual participant to self-acceptance, positive relationships and personal growth, all of which are elements of well-being, a state that is notoriously difficult to describe and even more difficult to measure. At the very least, meaningful interactions are likely to have a positive emotional carryover that will make the rest of the day better, regardless of whether the details of the encounter or the works of art discussed are remembered or forgotten.[4]

To what degree do the priorities of art history and curatorial decisions support this inclusive practice of interpretation and serve the needs of this audience? To be sure, as each program is carefully planned, art-making practice, criticism and history all figure into the process of choosing which works to share with participants, but further consideration of the particular needs of individuals with cognitive impairment and those who care for them determines the final selection. It is essential that individuals with dementia and the care partners who accompany them to museums have the opportunity to experience the canonical works, but there are other considerations one must take into account, including scale, sightlines and cultural sensitivities. This essay explores those considerations and highlights the flexibility that is required to balance audience needs and expectations while gently encouraging participants to explore new ways of engaging with art.

Understanding the needs of people with dementia and their care partners

Dementia is a general term for decline in mental ability severe enough to interfere with daily life. Alzheimer's disease accounts for 55% of all dementia diagnoses. Other types include vascular dementia, Lewy body variant, Parkinson's and dementias of other origins.[5] Accordingly, most participants at Arts & Minds carry a diagnosis of Alzheimer's, but programs are open to all those living with dementia and their care partners, who are themselves at risk of high emotional stress and poor health.[6] Symptoms of dementia include problems of attention, language, visuo-spatial perception, executive function and memory. Alzheimer's disease and other diseases that cause dementia are progressive and ultimately fatal. Working in the UK in the 1990s, social psychologist, Thomas Kitwood (1937–1998) launched the person-centered care movement for dementia, defined the main psychological needs of people with the disorder and diagramed them in this widely reproduced floral image, which places inclusion, occupation, identity, comfort and attachment around the central need of love (Figure 1).[7] Museum programs can touch on each of these in the following ways: visitors are welcomed into the museum and made to feel comfortable (inclusion and comfort). The focused activity of encountering works of art allows each viewer to experience his or her identity by thinking and feeling when responding to works of art and expressing those responses (occupation and identity). In the process, existing attachments between care partners can be reinforced and new attachments can be initiated. Finally, love is expressed in the action of the educator through careful preparation and mindful facilitation. While there is evidence that cognitive leisure activity delays the onset of dementia, no one is claiming that it will halt the progress of disease. More important perhaps, and certainly more realistically,

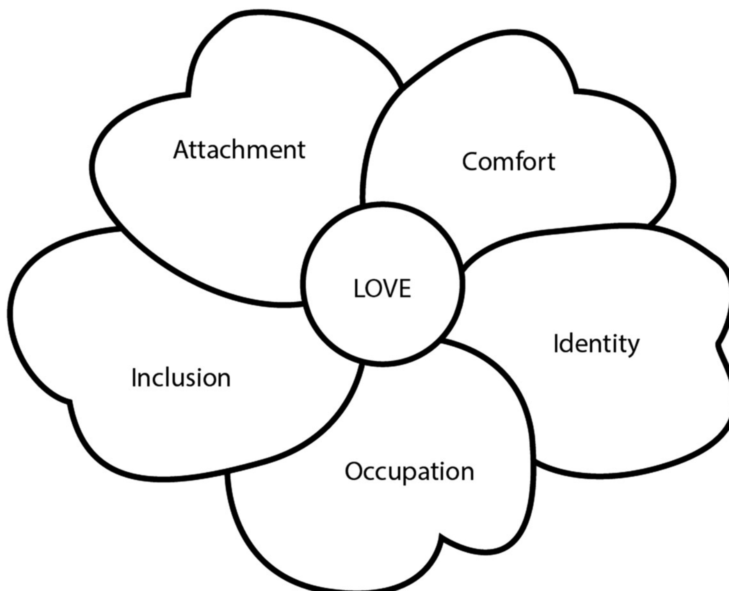

Figure 1. Well-crafted museum programs can meet the main psychological needs of people with dementia as diagramed by Tom Kitwood. *Dementia Reconsidered: The Person Comes First,* 1997, p. 82. Reproduced by permission of Open University Press.

such programs contribute to the kind of high quality, person-centered care that may improve well-being for people living with dementias.[8] Our task as museum educators is to understand the unique needs of this population as well as the mission and character of each museum. In so doing, we are fulfilling the directive, declared one hundred years ago by John Cotton Dana, the visionary director of the Newark Museum; "learn what aid the community needs: fit the museum to those needs."[9]

The development of museum programming for this audience first by educators at the Museum of Modern Art (MoMA) in 2006 and subsequently by The Metropolitan Museum of Art, Arts & Minds and more than 100 museums around the world, coincides with the state of museum education at a moment in its history when it is particularly receptive to the notion of shared meaning making. The historical tension of the didactic and the aesthetic that has marked the evolution of museum education practice since its founding in the early years of the twentieth century now seems able to hold expert knowledge, social and cultural context and visitor experience in equilibrium. While the curatorial voice will always be highly valued in museums, top-down modes of interaction are now more frequently balanced by interactive practices that encourage visitor response. In *Teaching in the Art Museum*, museum educator Elliot Kai-Kee concludes his chapter on the history of the profession citing debates about relativistic interpretations that began in the 1980s and which continue to inform our practice as educators.[10] While there will always be ideological camps that advocate for particular pedagogies, the educator who operates in the fluid space between art and the public, an ever-changing domain, must cultivate a flexibility of approach that keeps received knowledge, the physical realities of the object itself and visitor response dynamically in play. The dialogic approach to interpretation brilliantly described and theorized by Kai-Kee and Rika Burnham in the same book, offers wonderful possibilities for engaging the audience of people with dementia and their care partners. Older adults, including those who have had little exposure to museums, have a large history of experience and knowledge to draw on and people with memory impairment force us to be in the here- and-now. The dialogic approach draws on these strengths in ways that are expansive, inclusive and democratizing, and supports all participants regardless of health status.

In a recent JME article, Katherine Lamar and Jessica Luke reported on program impact on participating dementia care partners at three art museums. Care partners "reported the importance of the art within the program," suggesting that object choices may be important to care partner well-being and supporting the idea that the epistemological object is of central importance to the interaction. Their results also suggest that care partners experience alleviation of stress.[11] Similarly, in a pilot study conducted at four art museums in New York, Hannah Roberts et al. report that museum programs are associated with less dementia patient apathy and better care partner well-being.[12] A study undertaken at the Art Gallery of Hamilton, Ontario, showed the importance of care partner involvement, opportunities to share opinions and validation of personhood for individuals with dementia. They noted that care partners observed improvements in creativity, communication, relationship forming and task accomplishment in the persons they care for. In addition, some study participants reported reduced personal stress.[13]

Positive impacts on patients' and care partners' health such as these are dependent upon high quality program content and expert program facilitation. Thus, the choices educators make about which objects to attend to are crucial to potentially transformative

interpretive dialogues and may have serious implications for participant well-being. While the "wrong" choice will certainly not cause harm, the "right" choice has the potential to catalyze self-exploration as well as provide the opportunity to reflect on the past, to empathically connect with others, and to imagine new ways of being as one ages, particularly in the face of life-altering cognitive impairment. For this reason, museum educators at The Art Institute of Chicago and the Phillips Collection have chosen to collaborate with art therapists particularly for the art-making component of their programs.[14] Compassion and mindfulness, valuable for all human interactions, are absolute necessities for effective work with care partners and people with dementia. Arts & Minds educator training cultivates these practices under the guidance of an experienced social worker whose coaching strengthens our approach as art historians, artists and educators committed to a person-centered strategy.

Choosing objects – goals of experience weighed against the value of canonical objects

The choice of objects for collective looking and conversation is contingent upon a set of intersecting criteria, with the ultimate aim of creating a positive encounter. Because the audience of people with dementia and their care partners is among the most heterogeneous in terms of race, ethnicity, age, religion/no religion, level of education and health status, programs must be designed in ways that are truly flexible and which do not aim towards a predetermined outcome. Instead, together with our group of participants, we aim to co-create aesthetic experience and a dialogue of meaning making. It is helpful to realize that individual members of a diverse group will certainly have different expectations for what may unfold during a museum visit. Seeking to understand what visitors want when they come to museums and what they find enjoyable during their time there, Zahava Doering, Senior Social Scientist at the Smithsonian, organized the experiences visitors find most satisfying into four categories, a useful schema because it addresses not only issues of the objects and how they have been interpreted by academic disciplines including art history, but especially because it attempts to define different ways people engage with objects. Through a process of surveys, observation and analysis, Doering posited that visitors may enjoy object experiences, cognitive experiences, introspective experiences and social experiences.[15] Object experiences focus on something outside the visitor. They include "seeing the real thing," such as original, rare or valuable objects and being moved by beauty. This is the type of experience that most frequently centers on the canon. Cognitive experiences focus on the intellectual aspects of the experience, and may also include gaining information or knowledge, or enriching understanding through contextualization. Introspective experiences focus on private feelings and experiences and may involve imagining other times and places, recalling one's travels, childhood or other memories. Feeling a spiritual connection or sensing belonging are also aspects of the introspective experience as defined by Doering. The fourth category, social experiences, involves spending time with friends, family or other people. Each type of experience can be evoked in a well-facilitated dialogue with works that may or may not be of great art historical significance. Knowing the diversity of the Arts & Minds audience, educators must plan programs that embrace all types of viewers including avid museumgoers, artists and academics as well as those who may be entering a museum for the first time.

This is not to say that our only goal is to meet preconceived expectations. On the contrary, we hope to introduce all visitors to new ways of looking at and interpreting art. What we provide is time for art in the company of others sharing similar life-altering health challenges in spaces quite separate from those typical of daily activity. In New York City, the separation between the bustling street and the serene interior of the museum is particularly pronounced. The museum provides a sort of stage set, so to speak, for participants and educators to perform the process of collective looking and interpretation supported and surrounded by what art historian Carol Duncan describes as the ritual features of the art museum, "a marked-off, liminal zone of time and space in which visitors, removed from the concerns of their daily, practical lives, open themselves to a different quality of experience."[16] By foregrounding the object, whether canonical or not, co-created art conversations have the capacity to weave together the individual and the collective to form experiences that are cognitive, social and introspective. Object selection for meaningful collective experience is an overlapping, yet distinct process from "masterwork" selection.

Accessibility, exclusions and inclusion

The criteria for selection of objects for any given program are focused on the desire for participant experience of this sort, as much as on the work of art itself. Therefore, the educator's selection process is necessarily different from that of the art historian, weighing more towards participant needs and slightly away from the canonical value of the selected works. As with any group of visitors to our museums, accessibility is of the utmost importance. The object must be well illuminated. Visitors must be able to get close enough to the object to be able to see it. It must be large enough to be viewed simultaneously by all members of the group and the gallery must be able to accommodate 6–12 viewers seated in a semi-circle on portable gallery stools, in sturdy chairs or wheelchairs. Finally, it must offer clear sightlines. A certain subset of works in any museum will unfortunately be ruled out because of problems of physical accessibility. Curatorial decisions to hang works high on the wall or in positions obstructed by stanchions or crowded into corners render objects unfit for group experiences. This is a common source of frustration for educators in many museums: Objects may be beautifully installed for the individual viewer, yet nearly impossible for all but very small groups of agile visitors to look at together. These challenges are sometimes compounded in special exhibitions, where the narrative thread or historical argument is strong and installations are geared towards crowds of individual viewers, who are normally standing rather than seated in wheel chairs or on gallery stools. In all programs designed for group experiences, the physical conditions of display must be taken into account.

Within the works themselves, there are some exclusions as well. New media works that involve loud sounds or potentially disturbing lighting such as strobe effects that may be confusing, abrasive or disorienting, are not usually appropriate for individuals with neurological impairment. Sometimes it is the imagery or the content of a work that shifts it out of the realm of possibility. In 2010, as we were launching the first Arts & Minds programs at The Studio Museum in Harlem, Kori Newkirk's *Untitled*, was placed close by Rashid Johnson's *Death is Golden* (Figure 2). The Newkirk piece offered an inspiring possibility for the focus of a session, with the wire shopping cart so familiar to city dwellers now

Figure 2. Objects that offer rich possibilities for dialogue unfortunately may be precluded from programs because of the proximity of unsuitable works. Kori Newkirk, *Untitled* and Rasheed Johnson, *Death is Golden* from *30 Seconds Off an Inch* at The Studio Museum in Harlem, November 12, 2009-March 14, 2010. Photo courtesy The Studio Museum in Harlem.

transformed by the artist with the addition of brightly colored Plexiglas hinting at church windows and all the meanings this combination suggests. It was not hard to imagine the rich exchanges that might have taken place. However, because of the proximity of Johnson's piece, which consisted of the single word "Death" spray painted in gold letters on paper it would have been insensitive in the extreme to bring older adults in fragile health into the gallery. Because it was so obviously completely off limits, it was rather funny at the time, but in retrospect it is sad to think we missed out on Newkirk's work, which offered so much fuel for positive dialogue.

Any thoughtful museum educator will rather easily eliminate the spaces and works that present stark physical or psychological obstacles. Outside of these clear exceptions, nothing is off limits and the whole of the museum's collections and exhibitions are potential sites of group encounters. That being said, sculpture in the round can sometimes be difficult for individuals with compromised visuo-spatial perception, though confusion can be ameliorated if an object is backed by an unadorned gallery wall. An uncluttered visual field greatly aids perception. Crowded, Salon-style hangs can be confusing. Representational painting, particularly narrative works, may offer the easiest common starting point to get people looking and responding. Yet over time, as participants become familiar with the predictable rhythms of looking and talking together and grow to trust the educators and the museum experience, even the most advanced conceptual work becomes accessible.

Because of our commitment to access for all, educators would not pass by the works that have been given pride of place by the curators to hustle people with dementia into a quiet side gallery. Part of the very reason for programs like Arts & Minds to exist in museums is to push back against fear and stigma by including everyone in our programs

and also in the main offerings of the museum. The canonical objects, as chosen by curators, are there for all visitors. Fortunately, at each of our museum sites, we usually have the chance to visit an exhibition or permanent collection installation several times with the same group of people. This means that we can focus on work in the same galleries repeatedly over the course of an exhibition cycle. In the process, we explore the galleries quite fully, devoting the first program in a series to viewing and discussing the most prominent work on exhibit, and later in subsequent meetings introducing less obvious works, which may hold the promise of deeper, more vibrant engagement. We respectfully offer participants what they desire, often before we invite them to consider works that we think will be good for them. This approach helps to build an atmosphere of equity and trust and participants know their tastes and interests are valued by the facilitating educators. By going with the occasional crowd pleaser, we are gently pushing back against the authority of the canon and dispersing our own authority as knowledge experts, thereby furthering the spirit of solidarity and accompaniment that we work to cultivate.

Surprising choices – intuiting powerful experiences

Educators are always looking for art that promises an interaction that will "click," one where each participant has looked closely at a work of art, considered what it may mean and perhaps experienced beauty or wonder in the encounter. In addition, time and the company of others are key ingredients to a meaningful experience. An unhurried atmosphere encourages everyone to be in the moment, so to speak, and to allow the dialogue to develop. Moreover, personal connections to objects are often of great interest to Arts & Minds groups (as they may be to other audiences), whose members come to know one another over repeated visits.[17] Of course, the works of art themselves are of paramount importance.

Keeping these considerations in mind, simultaneously accounting for limitations in the installation, and predicting visitor responses to selected art works, educators anticipate meaningful experiences. But of course, what the participants bring to the dialogue is largely unknown and it is their contributions that form encounters of particular richness. One such experience took place as we considered *Black Star Liner*, by Jamaican artist Dudley Irons (Figure 3). The piece was part of *Caribbean Crossroads*, a major 2012 exhibition that explored Caribbean culture across three centuries. At The Studio Museum, Jacob Lawrence's canonical *Toussaint L'Ouverture* series was the primary masterwork. But on this particular afternoon, a small group of Arts & Minds regulars gathered instead around the far less known sculpture displayed on a pedestal in the center of the gallery and we began by looking quietly together. Soon viewers noticed that the piece is made almost entirely of matchsticks, that the surface is decorated with multi-colored stars and the words "BLACK STAR LiNER(A)" (*sic*). There is a gun mounted on the bow. One participant was curious about the words. She knew of the famous White Star Line, in fact her husband's grandfather had sailed on the Titanic and survived the disaster. A member of the group noted that Black Star Line was the name of Marcus Garvey's steamship company and shared a bit of history of the United Negro Improvement Association (UNIA) and the Back-to-Africa movement in the years following World War I. The subject of ocean liners brought further revelations: We heard that one long-time participant had escaped the holocaust in Europe, arriving alone by boat in New York when he

Figure 3. Non-canonical works may involve participants as much as canonical objects. Notice Jacob Lawrence's Haitian Revolution prints in the background. Dudley Irons, *Black Star Liner* from *Caribbean: Crossroads of the World* at The Studio Museum in Harlem, June 14 – October 21, 2014. Photo courtesy The Studio Museum in Harlem.

was only 6 years old; the grandfather of another was an officer on the White Star line. Hearing this, a care giver participant shared that her uncle shoveled coal in the boiler room of ships on the same line. The difference in status between the White officer and the Black worker below decks was quietly acknowledged by all. One gentleman shared that he had built many models, though mostly of airplanes. When planes were mentioned, the wife of a participant with dementia who was unable to speak, the grandson of the ship captain, shared that her husband had been a pilot in the Royal Air Force and was shot down over France in World War II. At that, the model builder rose from his seat and came around to stand face to face with the older gentleman who was seated in his wheelchair and the two men gravely shook hands, the wave of respect and admiration rippling outward to encompass the entire group. The utterly transformative experience that many of us experienced that afternoon could not have been anticipated. How beautiful it is that it was brought about by a work of art, both humble and majestic, which when seen and discussed together resonated with extraordinary depth.

One of the great pleasures of working with older adults with or without cognitive impairment, is the willingness they sometimes have to offer their own perceptions and insights and to peel back layers of meaning in the work that is the object of our contemplation. They are often willing to hear the ideas and opinions of others and are open to consideration of alternative responses. I think of this as a kind of wisdom that is born of age, experience and sometimes from vulnerability. As the niece of the boiler room worker, reflecting on the meaning of sharing art together remarked, "The experience of everyone enriches everyone." In this she included individuals with dementia, professional and family caregivers and educators. With so many considerations in play, the selection of objects and the facilitation of successful programs is a complex and subtle undertaking. The canon of art history and the curatorial voice may provide touchstones, but they needn't dominate the educator's choice. While our goal is to facilitate a meaningful encounter, getting there is not a straightforward, instrumental process. And while we are coming to appreciate and understand the many intellectual, social and spiritual benefits of encounters with art, our work is decidedly not utilitarian, but rather it is far less direct and far more powerful.

Notes

1. Both individuals with dementia and care partners are regarded as participants and are referred to as such in this article.
2. Arts & Minds was founded in 2010 by James M. Noble MD, Assistant Professor of Clinical Neurology, Columbia University and independent museum educator Carolyn Halpin-Healy. Programs take place at The Studio Museum in Harlem, The New-York Historical Society, The Jewish Museum, El Museo del Barrio and The Metropolitan Museum of Art. www.artsandminds.org.
3. Freire, *Pedagogy of the Oppressed*.
4. Guzmán-Vélez, Feinstein, and Daniel Tranel, "Feelings without Memory."
5. Dugue et al., "Review of Dementia."
6. Shaw et al., "Longitudinal Analysis of Multiple Indicators."; Barrow and Harrison, "Unsung Heroes Who Put Their Lives at Risk?"
7. Kitwood, *Dementia Reconsidered*.
8. Camic, Tischler, and Pearman, "Viewing and Making Art Together"; Eekelaar, Camic, and Springham, "Art Galleries, Episodic Memory and Verbal Fluency."
9. Dana, cited by Silverman, *The Social Work of Museums*, 139.
10. Burnham and Kai Kee, *Teaching the Art Museum*, 48.
11. The Frye Art Museum in Seattle, The Dallas Museum of Art and The Detroit Institute of the Arts.
    Lamar and Luke, "Impacts of Art Museum-based Dementia Programming."
12. Roberts, McGinnis, and Noble, "Museum-based Creative Arts Programming."
13. Hazzan et al., "Impact of the 'Artful Moments' Intervention."
14. Livingston, Persin, and Signore, "Art in the Moment." Rosenblatt, "Museum Education and Art Therapy."
15. Doering. "Strangers, Guests, or Clients?"
16. Duncan, *Civilizing Rituals*.
17. Williams, "Honoring the Personal Response."

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About the author

Carolyn Halpin-Healy, MA, Executive Director of Arts & Minds, is a museum educator whose work is dedicated to improving quality of life through engagement with the visual arts. In 2010 she founded Arts & Minds with neurologist James M. Noble, MD to provide museum-based programs for people with dementia and their care partners. She teaches at The Metropolitan Museum of Art and Union Theological Seminary.

ORCID

Carolyn Halpin-Healy http://orcid.org/0000-0001-9413-7654

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