1. Type of program: Symposium

2. Title of program: A Social Ecology of Dementia: Social Justice and Person-Centered Perspectives
   First index term 2 Aging
   Second index term 28 Ethics

3. Brief Content Description: This symposium will address the social problem of dementia and explore retheorizing about dementia and a full range of lived experience that may be associated with what we call a social ecology of dementia.

4. Division to submit this proposal: 24 - Society for Theoretical and Philosophical Psychology

5. Length of time requested on program: 50 min.

6. Chair(s) of the session:
7. Participants:

(1) Kerianne Morrissey, BA
Mailing address: 7 Ellis Drive, White Plains, NY 10605
Professional stage: Graduate Student
E-mail address: kemorrissey@gmail.com
Phone numbers: 603-727-9437 (home), 914-216-9961 (cell)
Institution/company: Vermont Law School, Lebanon, NH
Membership status: APA Member
Title of presentation: Critical Lens on Lived Experience of Dementia: Limitations on Rights of Capable Self
Electronic Archiving: No
Coauthor 1: Mary Q Morrissey, PhD, JD, Fordham University, New York, NY

(2) Mary q Morrissey, PhD (Submitter)
Mailing address: 7 Ellis Drive, White Plains, NY 10605
Professional stage: Advanced-Career Professional
E-mail address: morrisseymarybeth@yahoo.com
Phone numbers: 914-714-2241 (cell)
Institution/company: Fordham University, White Plains, NY
Membership status: APA Member
8. Discussant(s):

(2) Scott Churchill, PhD
Mailing address: psychology, University of Dallas, 1845 E Northgate Dr., Irving, TX 75062
Professional stage: Advanced-Career Professional
E-mail address: bonobo@udallas.edu
Phone numbers: 1-919-744-7134 (cell)
Institution/company: University of Dallas, Irving, TX
Membership status: APA Member
Title of presentation: “Enjoy Yourself—It’s Later than You Think’: Medical Politics of Dementia and Elder Care
Electronic Archiving: No
Coauthor:

(3) Bruce Jennings, MA
Mailing address: Vanderbilt University, 2525 West End Ave. Suite 400, Nashville, TN 37203
Professional stage: Advanced-Career Professional
E-mail address: brucejennings@humansandnature.org
Phone numbers: 615.875.9913 (office)
Institution/company: Vanderbilt University, Nashville, TN
Membership status: APA Member
Title of presentation: In Solidarity with Dementia
Electronic Archiving: No
Coauthor:
(1) Suzanne Kirschener, PhD
   Mailing address: Psychology, College of Holy Cross, 1 College Street, Worcester, MA 01610
   Professional stage: Advanced-Career Professional
   E-mail address: skirschn@holycross.edu
   Phone numbers: (508) 793-2011 (office)
   Institution/company: College of Holy Cross, Worcester, MA
   Membership status: APA Member

(2) Louis Sass, PhD
   Mailing address: Psychology, Rutgers University, 57 US Highway 1, New Brunswick, NJ 08901-8554
   Professional stage: Advanced-Career Professional
   E-mail address: louissass@aol.com
   Phone numbers: 732-662-2664. (office)
   Institution/company: Rutgers University, New Brunswick, NJ
   Membership status: APA Member

9. Accommodation request: None
10. Submit for CE: False

Received: 12/3/2018 4:47:56 PM
A Social Ecology of Dementia: Social Justice and Person-Centered Perspectives

A reframing of the problem of dementia invites retheorizing about dementia and a full range of experience that may be associated with what we call a social ecology of dementia. Such a reframing challenges conventional notions of the self, continuity of the self over time and self-other relations, and the norms by which the society regulates self-governance and participation in civic and economic life. In this symposium session, critical theoretical perspectives in psychology will be brought to bear in helping to deepen understanding of the lived experience of dementia and its multiple historical, social and cultural contingencies including the sociopolitical context of neoliberal philosophy. Arguments will be advanced that challenge existing social and economic structures driving aging and health policy making concerning dementia care, such as the successful aging paradigm, and concomitant social and cultural practices of hegemony and appropriation that marginalize persons with dementia as fully agentic members of the society. Panelists will explore new ways of thinking about the experience of dementia from person-centered perspectives persons. Implications for psychology and a psychological humanities will be discussed.

(1) Critical Lens on Lived Experience of Dementia: Limitations on Rights of Capable Self

The global public health problem of dementia and the challenges presented by design of dementia care systems both in the United States and internationally raise serious questions about the goals of science and scientific research in the context of a dominant neoliberal sociopolitical philosophy that marginalizes the person with dementia and such person’s very personhood. Through theorizing that seeks to expand the body of critical theoretical scholarship addressing neoliberalism to critiques of the experience of aging and more specifically, to aging and living through dementia, the authors challenge existing legal and ethical frameworks governing decision making that may deny persons with dementia their personhood and the possibility to be meaning-makers and agents in ways that are not entirely accessible by capable persons. The tensions between rights-oriented frameworks and frameworks that recognize the values of community and solidarity, and their relevance to the hegemonic practices of capable persons with regard to those who are less than fully capable, will be explored. Implications for a humanistic psychology as applicable to persons with dementia and informal and formal caregivers will be discussed, as well as the response of a psychological humanities that may be poised to re-educate communities of scientists and professionals about the broader goals of dementia care.
(2) “Enjoy Yourself – It’s Later than You Think”: Medical Politics of Dementia and Elder Care

Anyone who has tried to assist one of their aging family members adjust to the limitations of aging, has come into contact with the medical establishment at every step along the way. The difficulties of traversing this field entail the endless minutia that one must attend to in the process of bringing in one’s loved one for ongoing medical care, not to mention the horror of dealing with seemingly insurmountable crises that leave the loved one dependent and unable to make decisions for their own care, even while they strive so hard to remain a vital part of their families.

We find the aging family member trapped in a body that is no longer the able vehicle of their being-in-the-world: the body heretofore known as the “I can” has more and more revealed itself as the “I can’t”. Failing memory and cognitive skills make it difficult to keep track of all that is assailing one simultaneously. And yet, in the midst of all the chaos and confusion, our loved ones are sitting there trying, at some level, to make sense of it all.

What is the nature of the interface of such a patient with the system of operationalized medical care as it is known today? How does the bureaucracy of the medical system serve to alienate the patient even further from the care she so desperately needs? And finally, how do healthcare personnel themselves become vulnerable to the bureaucracy, which puts them into double binds – on the one hand trying to follow nursing protocol, and on the other trying to follow their hearts?

This presentation will attempt to gather the perspectives of elder-patient, elder-care staff, and family in order to examine both the "social ecology" of our relationship to the institutions providing treatment and caring for our aging population, while also reflecting on the sometimes indifferent and even sinister policies within both the medical establishment and hospice organizations.

(3) In Solidarity with Dementia
This panel presentation will address two domains. First, it offers a discussion of the concept of quality of life and its application to setting the goals of dementia care. Second, it discusses the ethical issues of dementia care by focusing on the principles of right recognition (of agency, personhood and membership in the moral community) and right relationship (of attentiveness and solidarity).

It argues that in the case of serious cognitive impairment, such as Alzheimer’s disease in its early and middle stages, these principles can be respected in dementia care by actualizing continuing capability for meaning making agency and memorial personhood.

Meaning making (or communicative) agency differs from responsibility generating agency, and it provides a rationale for recognizing an individual’s continuing membership and considerability within a moral community even though the conditions for holding and taking responsibility for one’s actions no longer obtain.

Similarly, memorial personhood differs from what may be called narrative personhood, but it again sustains right relationship with those whose claim to respect on us is grounded more on who they were than on who they are; on the other hand, their claim to attentiveness and care comes from who they are (their present need and circumstance). Remembrance of memorial personhood consists of these two facets of respect and care.

This reframes dementia care from a deficit perspective to a capability approach and its practical implementation in long term care facilities, with goals beyond comfort and safety to include providing the social relational structures and resources necessary to enable the realization of remaining potential agency and functioning.