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The enduring self: personhood, autonomy and compassion in the context of community-based dementia daycare centers

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Abstract

Background: The aim of this paper is to explore the concepts of personhood and compassion, as perceived by staff caring for people with dementia (PwD) in community-based dementia daycare. Autonomy in the Western culture is closely related to concepts of personhood and form the cornerstone of person centered care.

Methods: Participants in this study were recruited from 100 multi-disciplinary professional staff members caring for 400 PwD, within the nonprofit day care centers of MELABEV. Fifty-two staff members agreed to participate in a face-to-face semistructured individual interview exploring staff attitudes and beliefs relating to death and grieving in the daycare center. The words autonomy, personhood and compassion were not used in any form in the semistructured questions. The responses to the open ended questions, were recorded verbatim and analyzed by a gerontologist, medical anthropologist, and a physician. This paper presents a Constructivist Grounded Theory analysis of the responses.

Results: From our analysis we identified three different constructs of personhood: sociologic, individual and biologic. These constructs were drawn from text and words and examples provided by the staff. Our analysis supports the notion that personhood is an evolving and non-constant construct in dementia care during the "ongoing funeral" trajectory of dementia. The staff's belief in the autonomy of PwD and their strong efforts to maintain person-centered care were documented. Our analysis also showed that staff members beliefs of autonomy and personhood are related to their capacity and desire to provide compassionate care despite their ambivalence as to what is the best way to provide this care.

Conclusions: We believe that our results support several research hypotheses for further investigation and point to possible teaching and educational methods and interventions for providing compassionate person-centered care in dementia day care. We suggest that our, Sustained Personhood Model for Dementia Care is intimately related to autonomy, a fundamental human right for all persons, including those with advanced dementia. The integration of the concepts of autonomy and personhood can be taught and enhanced within the concept of compassionate care.

Keywords: Dementia, Person-centered care, Personhood, Compassion, Autonomy, Adult daycare staff, Sustained personhood model for dementia care

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Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 2 of 10

Background

With the recent advancements in global inclusion efforts for people with all kinds of disabilities https://www.ga-daalliance.org/news/70th-world-health-assembly-adopts-global-action-plan-on-dementia and an increasing sensitivity to social and political harms caused by stereotypes, stigma, and discrimination based on disease, or disabilities [1], we see a resolution by academics, politicians and citizens toward a more compassionate and sustainable healthcare system that recognizes individuals capacities remaining in the face of disabilities including neurocognitive diseases. At the core of these advancements is the theoretical and philosophical constructs of personhood as modified through not only biomedical models of health but our socio-psychological and cultural understanding of autonomy, human rights, personhood, empathy, compassion and what makes us human. The pioneering work of Thomas Kitwood [2], who was at the forefront of those who challenged this biomedical approach, argued in favor of a person-centered approach to dementia that assumes that the person is present and approaches dementia as a condition shaped and defined by the social and interpersonal contexts rather than by neurological changes alone.

As our understanding of the neuroscience of dementia has evolved, the medical care system now recognizes DSM-V's classification 0–7 i.e. pathology present without disease manifestations [3], and as an unpredictable and very individualized disease trajectory, the issues of personhood and autonomy have become central to the caring of people with dementia (PwD). Although consensus is still evolving on the constructs of personhood and autonomy, there is a clearer understanding that personhood is not an all or nothing phenomenon, but rather an evolving and non-linear construct [4]. In the care setting, the valued concepts of preserving human dignity and autonomy in a compassionate manner, resonates with the construct of person-centered care - "the person comes first" [5]. Such constructs usually surface more prominently in end-of-life issues, especially in cancer palliative care but also arise in dementia care [6]. Dementia care, including the dementia day care setting, end-of-life issues, extend over a long period of time.

Given that the rate of dementia is expected to rise as the third most prevalent chronic disease by 2015 [7], the medical care system, and policy makers are beginning to recognize and address the constructs of autonomy, personhood and compassionate care, and how to create an evidence based, good practice guidelines, for implementation in the real world.

In our rapidly growing population with longevity and great advances in biomedical research and in healthcare delivery systems, along with a strong emphasis on economic productivity, some researchers suggest we have become a hyper cognitive culture [8]. Post uses the term "the deeply forgetful" to emphasize the presence of personhood even in persons with very advanced dementia. His gentler language, allows a more nuanced meaning of what happens to a person's autonomy and social interactions i.e. how people with dementia are incorporated or not in our society. Post's efforts to shift the paradigm of stigma, exclusion, and fear of dementia is of course well-founded, for even today we witness people referring to and treating PwD not as autonomous human beings but rather as "the living dead".

We are sometimes witness to PwD being treated as already dead and as walking corpses to be both pitied and feared, despite their obvious signs of life [9]. For example, it is disconcerting to find that PwD are frequently and overtly referred to as zombies both in scholarly and popular literature [10]. Book titles such as Alzheimer's disease: Coping with a Living Death [11] devalue PwD. The destruction of the person and the animation of the corpse is another theme: Cohen and Eisdorfer [12] titled their resource book for families of PwD, "The Loss of Self" and referred to the "death before death" while Fontana and Smith [13] to the "self that unbecomes". That dementia is defined as a "confused state between life and death" has been noted by Matthews [14] who cautioned that "it is easy to fall into thinking of dementia as a kind of living death".

Berger and Luckman [15] theorize about the power of language and suggest that the very words used to define, describe and relate to personhood in PwD is critical for their actual care.

Based on the social construction theory we can argue, as Kitwood does [16], that PwD suffer from "malignant social psychology" where PwD are first compromised, and then judged negatively, when they react to negative positioning with hostility, learned helplessness, or depression. Sabat [17] built on Kitwood's observation to develop a theory of "malignant social positioning" that encompasses two positions germane to PwD. First, there are interaction cases, "wherein what one person says positions another person", for example by highlighting their deficits, and second, reflexive cases, "wherein one positions him or herself" in response by either rejecting or accepting what is said. Sabat concluded that some forms of positioning can be malignant, "that is to say dangerous, insofar as they can have negative effects not only upon the ways in which dementia scholars have placed much of the blame for the powerful stigma regarding dementia on the dominance of the biomedical understanding of the disease" [18–21]. This model reinforces the notion of the PwD as a non-person, i.e. one whose brain has been destroyed by the disease and who therefore no longer exists as a person but only as a body to be managed. The practical consequences of this view

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 3 of 10

are profound: attempts to communicate with the patient stop, life-prolonging treatment is withheld, and force is used to control undesirable behaviors. Thomas Kitwood [22] who was at the forefront of those who challenged this biomedical approach, argued in favor of a person-centered approach to dementia that assumes that the person is present, and approaches dementia as a condition shaped and defined by the social and interpersonal contexts rather than by neurological changes alone. Kitwood's point was that what is understood by members of the medical profession as symptoms of the disease may in fact be the result of how PwD are treated, and how they are treated is the result of how the disease is socially constructed.

In our view a useful model that incorporates autonomy, personhood and compassionate care is Buron's [23] "Personhood Model for Dementia Care", (Fig. 1). The model recognizes three levels of personhood: sociologic, individual, and biologic, which are the building blocks for the construct of autonomy. In Western culture, autonomy has a range of different meanings such as "… self-rule, self-determination, freedom of will, dignity, integrity, individuality, independence, responsibility and self- knowledge" [24]. Autonomy is also identified with the qualities of intentional actions and being free from controlling influences. Autonomy is important for good quality of life [25]. Promoting autonomy is therefore considered an important aspect of person-centered dementia care [26]. In Buron's model staff focus their care on different aspects of personhood throughout the progression of the dementia. At the beginning stages of dementia the concentration is on sociologic personhood (i.e. where care is focused on the person's current membership in social groups – such as social relationships,

culture, responsibility, moral agency & memberships in professional & social groups like a daycare center). In intermediate stages of dementia the focus is on the individual personhood of PwD (i.e. care is focused on knowledge of the PwD and their embodied experience) [27, 28]. At more advanced stages of dementia the concentration becomes the biologic personhood (where care is focused on biologic/essential care needs such as physiological needs and pain management).

Methods

The research took place at MELABEV, Community Clubs for Eldercare in Israel, a non-profit organization, that operates 4 day care centers for over 400 persons with dementia ranging from minimal cognitive change to advanced dementia. It is important to highlight that all persons attending the day care center have a diagnosis of dementia from their doctor. Melabev staff evaluate each participant in order to personalize their day care activity program. This evaluation includes family interviews as well as interviews with the PwD evaluating not only their functional and cognitive status but their lived experiences; education, hobbies, likes, and other personal variables. This type of comprehensive evaluation allows the staff to provide personalized person-centered care within a smaller day care group, adjusted for dementia level (begining, intermediate, advanced). Each group is led by a group leader, usually a social worker who works together with a multidisciplinary team. Activities for all groups include music therapy, dance therapy, computer cognitive games, and horticulture, led by professional therapists. Nutritionally adapted breakfast, lunch and snacks are served at tables, arranged with the intention of increasing the personal connections and
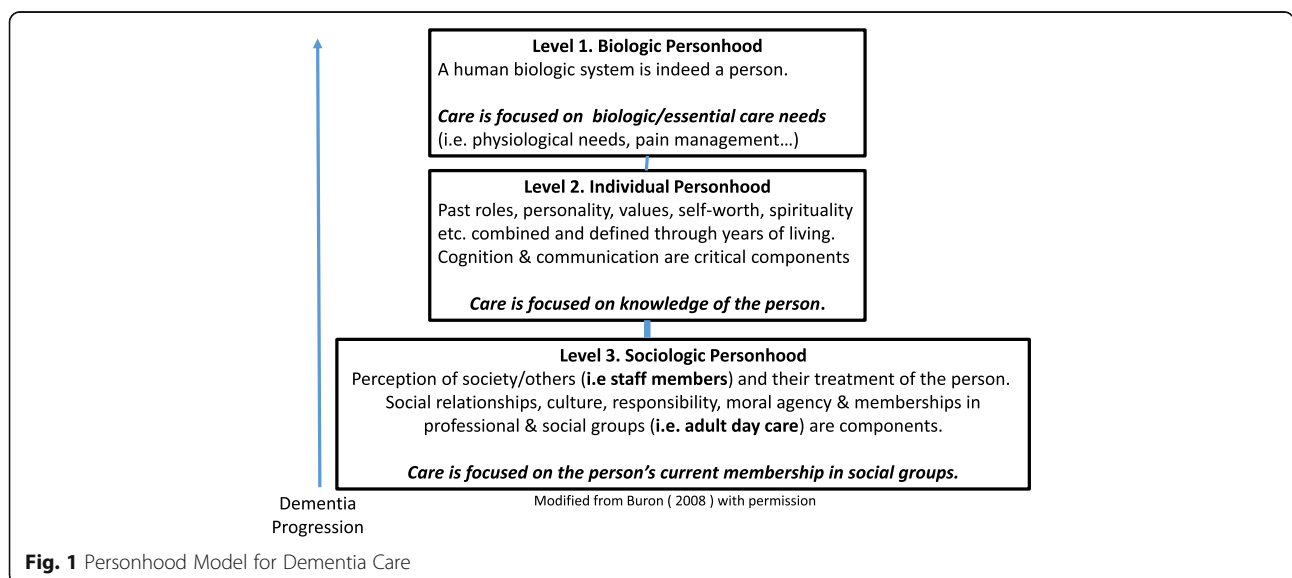

Level 1. Biologic Personhood
A human biologic system is indeed a person.

Care is focused on biologic/essential care needs
(i.e. physiological needs, pain management…)

Level 2. Individual Personhood
Past roles, personality, values, self-worth, spirituality etc. combined and defined through years of living. Cognition & communication are critical components

Care is focused on knowledge of the person.

Level 3. Sociologic Personhood
Perception of society/others (**i.e staff members**) and their treatment of the person. Social relationships, culture, responsibility, moral agency & memberships in professional & social groups (**i.e. adult day care**) are components.

Care is focused on the person's current membership in social groups.

Dementia Progression

Modified from Buron (2008) with permission

Fig. 1 Personhood Model for Dementia Care

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 4 of 10

interactions between the group members. The staff have regular meetings where they discuss each participant in the group and how they're progressing and adjustments are made based not only on objective findings but also input from the staff that relate to the level of comfort and sociability within the group. It is routine that as the disease progresses clients may be moved to a different level group in the day care center that is more suitable to their current capacities and needs. In this paper we use the term person-centered dementia care as incorporating personal knowledge of the person with dementia, conducting meaningful activities, making well-being a priority, and improving the quality of the relationships between the health care provider and the individual with dementia. In other words, incorporating the sociologic, individual and biologic personhood into the daily day care activities.

Ethical approval for this research was obtained from the *Shaare Zedek* Medical Center, in Jerusalem, Israel. The number of staff consenting to participate was 52 from a total pool of 100. These include activity workers, social workers, expressive art therapists, directors. The goal of the interviews was to explore attitudes of staff towards death, dying and mourning of PwD [29]. The semi structured interview instrument was created based on input from multidisciplinary professionals (authors included), and on the scant death and dying and dementia literature (e.g. [30–32]). Interviews ranged from 20 to 60 min. The interview included both closed and open ended questions. In the last question of this primary instrument, the staff were asked "Is there anything else you would like to add?" without specifying anything further. All interviews were conducted by one professional who was not a member of the MELABEV staff and the results were encoded to ensure anonymity and facilitate analysis. The free text responses were recorded verbatim and analyzed by a gerontologist, medical anthropologist and medical doctor. This paper presents a Constructivist Grounded Theory textual analysis of the open ended questions.

Methodologically speaking, it is important to delineate Constructivist Grounded Theory as defined by Charmaz [33] which is based on a social scientific perspective that addresses how realities are made, that is the dialects of lived experiences. This perspective assumes that people, including researchers, construct the realities in which they participate. Constructivist inquiry starts with the experience as perceived within the context of study and asks how members construct it. That is to say, the phenomena are explored from multiple disciplines and expertise and experiences, and the aim is to map the web of connections and constraints of the constructs examined. Therefore, the interpretation of the studied phenomenon are a construct themselves that addresses how realities are

made and how they can be useful in future endeavors and research.

The results presented below emerged following extensive and interactive analysis following the guidelines of Constructivist Grounded Theory within the context of the Buron Personhood Model of Dementia Care. We introduce first a real case study related during the interviews that exposes, in our view, the interactiveness of the constructs of autonomy and the various aspects of personhood.

Results

CASE study scenario:

> "Mrs. B, a PwD who attends the day care center, refers with sadness to the death of Mrs. D, a member of her day care group. It's already a month after she has died. At least twice she sighed and referred to this group member's death. Although she's in the low functioning group, she's aware of others, including her past husband. One can tell that she is sad and misses Mrs. D."

The major constructs of our Constructivist Grounded Theory analysis on perceptions of personhood, autonomy and compassion in caring for PwD include the following:

The autonomy of PwD is ever present and evolving

The overwhelming majority (98%) of staff members hold the belief that PwD are autonomous with subjective self and agency. Even those with severe dementia are viewed as adult autonomous individuals.

Staff believe that PwD maintain emotional capacities despite advanced cognitive decline. This can be seen in quotes from the staff such as "*This is an emotional memory. So yes, they can remember the feeling of loss,*" and "*Even if the head forgets the heart doesn't.*" As well as this quote related to the importance of memorial ceremonies "*…They have to have a place for expressing emotions.*"

The presence of emotional capacity is even viewed as present in people with advanced dementia as demonstrated by this quote "*Although she's in the group for people with more advanced dementia, she's aware of others, including her past husband who died.*"

The following related subthemes emerged which seem to follow the Buron Personhood Model of Dementia Care. Quotes from the staff interviews are included to highlight the concepts.

Sociologic personhood

It appears that the staff perceived a social structure and hierarchy within the group which in turn affected the staff's choice of action when a group member died. For example,

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 5 of 10

staff mentioned that the rituals and practices of grieving in the group, would "*depend on how well the other group members knew the person who died,*" or "*depend on the relationship between the clients and the deceased. There is a thought: why is he missing?*" or "*If the person was prominent in the group, (his absence) is more noticed.*"

In other words, group hierarchies and dynamics exist among PwD, and this social personhood affects staff practices. The ritual of death acknowledgement, interestingly enough, varied depending on the staff's perception of the social selfhood of the person who died within the PwD group.

> "*They ask and show emotion; they worry when someone is missing.*"

> "*I think it is important to tell people about this loss. If it is someone close they feel the loss without giving it a name. It arouses anxiety and discomfort, unease. Telling may make a person sad and mournful, but this is normal. If we want our clients to have the real life experience, it is part of it. Hiding makes things more and more complicated. Death and dying are essential parts of everybody's life experience.*"

The staff acknowledges the unique social personhood of each PwD which found expression in the social interconnectedness that emerged from diverse practices relating to rituals performed to acknowledge the death of a group member, as well as from the actual staff practices in attending family initiated rituals connected to burial services.

> "*It's hardest with people [who die from the group, with whom] I have relationships with.*"

> "*It can be devastating to lose a client with whom you've built up a meaningful relationship, especially when there's no prior preparation for the event (unpredictable). There can be a heightened reluctance to bond with other Melabev clients in the wake of such a jolting awakening.*"

> "*When I was sick in hospital, 2 - 3 people (clients) called, cared, asked when I'll be back.*"

The staff quotations demonstrate an interconnectedness and emotional connection – both between the staff and the PwD, the PwD and the staff and between the group members amongst themselves.

Staff also mentioned rituals that staff members themselves do after the death of a group member. They go to the funeral and they visit the mourner's home. One center even sends a letter to the family on the 1 year anniversary of the death so the family knows the person has not been forgotten. This demonstrates staff-client interconnectivity – an aspect of personhood.

> "*In a group setting, if we talk about a client dying, it also tells them that we will remember them once they die.*"

Individual personhood

Given the staffs' strong beliefs in the principals of human autonomy, it is not surprising that 60% of the staff interviewed also expressed the belief that PwD have the "right to know" of the death of a member from their group as seen in the following quotes:

> "*Our clients are entitled to know about death and losses and it is our job to help them and their families cope with them.*"

> "*We need to be honest and tell the client gently.*"

The staff focus on the capacities of the PwD as seen here;

> "*The social worker or staff member who feels comfortable telling - in as positive a way as possible, stressing how to honor the person and, if possible, to say something of how he died (authentic, not a lie). People (with dementia) are stronger than we think.*"

These following quotes demonstrate how staff members try to look at the group members as the individuals that they were – looking past the dementia that they must now cope with.

> "*If someone would have asked the client when he was healthy, (whether he wanted to be told when someone died) the answer would be yes.*"

> "*We have to work as if he is like before his mind was affected. Give the same respect. It's important for their emotional life. He feels that someone is not there (has died).*"

> "*They can (understand death) ... There are those with life experience, (who) dealt with death (in the past).*"

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 6 of 10

The staff believe that not all PwD are alike. They are unique human beings with unique feelings– as seen from this quote *"it also depends (whether or not to tell the group) on their frame of mind or mood that day."*

The event of a death in the daycare center is used by staff to acknowledge the personhood of the PwD left behind in the group as seen from the following quotes;

"(We) do a kind of memorial ceremony to honor their memory, to convey we honor them- as maybe they want also to be honored (eventually)."

"If you don't commemorate and just ignore the death, when people see that when someone's not there, they feel that when they pass away the same will happen to them - no one will care."

Biological personhood

Staff recognized and reported that they have observed changes in some group members following the death of someone close to them, either a family member or another group member. These include observing changes in the client's behavior, dietary patterns, and affect, which we constructed as staff acknowledgment of the biologic personhood as it is interconnected to the sociologic personhood aspects.

The staff include all group members in memorial services. This includes people who can't participate in any visible way in the service. Those who might just sit in their chair staring into space with a blank look throughout all the days activities. These are the members who we would think only need their biologic/essential care needs catered to, but they are also included in the group rituals in some way (sitting in the circle with the other group members during a memorial service), in order to give opportunities to reach their individual and sociologic personhoods even when they seem to only need care of their biologic personhood. Although someone may be in a low functioning group they are given the opportunity to be human and participate in some way in the mourning process, just as the rest of the group.

Limitations

The current study is based on interviews with a relatively small group of staff members who consented to participate. We postulate that non-participants may have different views.
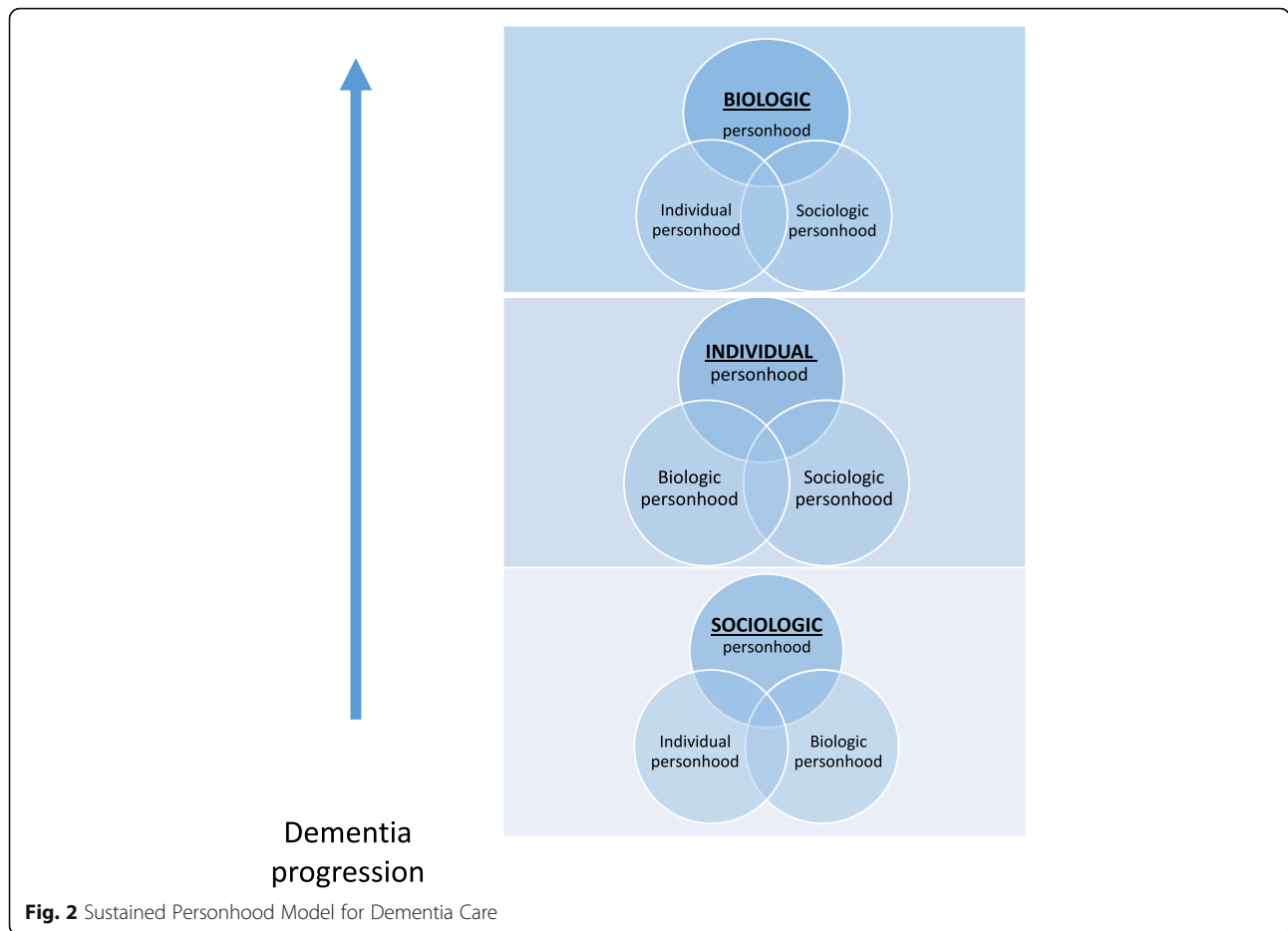
Discussion

The strongest theme that emerged from our analysis is that the staff members base all their work on the very basic concept of personhood. Cecchin [34] points out that attention to preserving personhood in caring for

dementia is essential for the physical and mental well-being of PwD. Harrison [35] equates the establishment and maintenance of personhood with well-being. Staff members that were interviewed perceived the PwD as having agency and individuality, acknowledging various levels of personhood [36]. These concepts emerged especially relating to the rituals organized in the event of a death in the group, and also in staff's perception of the PwD's status in the day care group setting. Staff recognized the personhood of the deceased group member, as well as the personhood of the PwD left behind still able to attend the group.

As mentioned above, Buron's "Personhood Model of Dementia Care" [37], (Fig. 1) recognizes three levels of personhood: sociologic, individual and biologic. As the dementia progresses staff focus on a different level of personhood: sociologic in the begining stage, individual in the intermediate stage, and biologic in the advanced stage. We would like to suggest that our data support a slightly modified model of personhood, where the sociologic, individual, and biologic constructs of personhood, as seen by the daycare staff, can remain interwoven even in the most advanced stages of dementia. During all stages of dementia, caregivers remain aware of the sociologic, individual, and biologic personhood of the PwD. This "Sustained Personhood Model for Dementia Care" is pictured in Fig. 2, by the intertwined circles. As the dementia progresses, the personhood that becomes the focus is the one in the circle that is on the top of the three intertwined circles, (that is capitalized, underlined and bolded). However, as our study shows, staff strive to address all three types of personhood throughout the dementia progression since all aspects of personhood are inter connected.

Focusing on the personhood at the social level by the daycare staff contributes to the quality of care they provide. Staff's endeavors to enable social level, create an environment of stability, socialization, and support during the lengthy "ongoing funeral" process [38]. This contributed to the quality of care they provide. Since our study was among staff at daycare centers, our findings about personhood and autonomy may be somewhat different than that reported in nursing home settings (e.g. [39, 40]).

We would like to suggest that the strong theme of autonomy in PwD may be the construct that supports person centered care. There are various definitions of personhood. The definition of Kitwood [41] suggests that it is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being." This definition implies "recognition, respect, and trust" [42] which fits our findings to recognize the needs, wishes, emotions, personality, relationships (or need for relationships) and life story of the

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 7 of 10

Fig. 2 Sustained Personhood Model for Dementia Care

individual. Our staff recognizes autonomy, which is a key construct of personhood as the main reason that an individual, even with advanced dementia, has the right to know about the death of one of their group members. Our staffs self-reported perceptions relating to agency of PwD is consistent towards a more inclusive vision of dementia care [43].

The details of how to tell, who should tell, when to tell, appear to be dependent not so much on the biologic personhood, but rather on the sociologic personhood [44]. Their rituals of acknowledging death are highly dependent on the "social standing" of the individual in the group, even in advanced dementia. Thus, individual and sociologic personhood, when combined with the staffs' beliefs to tell about death, influenced the staffs' practices regarding the PwD's "right to know" and telling about death. It seems from our research that the staff feel, that the individual and sociologic personhood remain even in advanced dementia. This is reflected in Fig. 2, a "Sustained Personhood Model of Dementia Care".

We found the personalized mourning rituals conducted by the staff as a theme that reflects the staff attitude of different levels of sociologic personhood, regardless of the stage of dementia. Therefore, we suggest that emotional capacity is a variable that the staff takes into consideration when conducting rituals and is consistent with their belief of the autonomy of the PwD. This is consistent with the literature that reports that PwD maintain a significant level of social agency [45]. The study by Boyle [46] highlights that "people with dementia who lack deliberative capacity can nonetheless demonstrate creative capacity for agency," which is part of the sociologic construct of personhood. The staffs' self-reported actions are compassionate and consistent with their beliefs.

Yet, despite the staffs strong beliefs about autonomy, personhood and therefore person-centered care (e.g. [47, 48]) some expressed ambivalence about "standards of practice" and a need for additional training. The literature shows that in nursing homes, some evidence-based studies indicate that person-centered care including autonomy, can be taught (e.g. [49–52]). However, only a few evidence-based practical guidelines for daycare staff on how to deal with death and grieving issues were published [53, 54] despite the studies describing that PwD may exhibit autonomy and emotional capacity even in advance stages [19, 55].

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 8 of 10

We would like to suggest that our pilot demonstrates that staff beliefs can be channeled into practices that build on a "teachable moment" framework for defining tools and venues to increase daycare staff capacity to implement their attitudes on personhood and autonomy in PwD.

A "teachable moment" is a concept that was popularized by Robert Havighurst in his 1952 book, Human Development and Education. In the context of Education theory Havighurst explained, "A developmental task is a task which is learned at a specific point and which makes achievement of succeeding tasks possible. When the timing is right, the ability to learn a particular task will be possible. This is referred to as a 'teachable moment'" [56]. The phrase sometimes denotes not a developmental stage, but rather "that moment when a unique, high interest situation arises that lends itself to discussion of a particular topic". When the student is personally engaged with the issues and problems [57].

These moments can (and often do) come when least expected. A "teachable moment" is often best demonstrated with a significant emotional or traumatic event, the emphasis being on the 'moment' and not on the lesson. (An example would be, after a car accident; when the use of a seat belt has obviously saved a life, or conversely, when a life has been lost when a seatbelt was not used). We would like to suggest that the death of a group member can be used as a "teachable moment" to teach staff about the "Sustained Personhood Model of Dementia Care".

Conclusions

Our findings indicate that staff members believe that PwD can socially communicate and understand death and grieving. This is based on their attitude that even people with severe dementia are unique individuals and persons that must be treated as autonomous.

Staff's beliefs and practices regarding death and grieving of PwD reveal a compassionate and person-centered approach that identify the emotional and social capacities of PwD despite their cognitive deficits. Therefore, staff believe that PwD have the "right to know" because of their subjective individuality and personhood.

The staff's personal fears and personal fears and anxieties regarding death and dying of a client need to be part of their continuing education and support since caring for the caregiver is critical for person-centered care. The staff's rituals about how and when to present and acknowledge the death of one patient is highly dependent on the PwD social standing as perceived by the staff. However, still questions about the best way to tell are still raised.

The ability to create models of care for PwD involves a variety of challenges including: Staff training implemented in an evidence based way, the built environment within which care is provided, and support for staff. Staff training should be implemented in an evidence based way. This is a real challenge especially in the area of compassion. Although we know how to describe and talk about compassion, the empirical evidence is still in its infancy. The workplace culture of the day care center, the built environment within which the care is provided, has to be conducive to compassionate care and include the culture of person-centered care [58, 59]. Here the role of managers and health policy reimbursement issues are of critical importance to maintain not only trained staff, but the appropriate ratio of staff/patient to provide services in a person-centered way. Finally the staff themselves need to be supported in their own personal dilemmas to avoid burnout and to be able to deal with dilemmas and conflicts that arise from different perceptions of autonomy between staff and the family of PwD.

Our small study seems to show that at the MELABEV centers they attempt to create an environment, which is not "malignant", but rather one that enables the staff to promote the personhood and autonomy of PwD at all stages of the disease.

In the paucity of any evidence-based research or consensus of good practice guidelines, we believe that the topic of maintaining autonomy and preserving personhood through compassionate personalized person-centered care is worthy of further research. We believe that a dialogue of how to teach, train and support daycare center staff based on a "Sustained Personhood Model of Dementia Care" combined with the concept of "teachable moments" is warranted useful. Such a staff training program on PwD would benefit from a multidisciplinary approach. Such an approach should include physicians, nurses, activity workers, gerontologists, and medical anthropologists and sociologists, who would have the strong theoretical framework to highlight 'personhood' and its different dimensions. There is also a need, at the theoretical level, to expand social science research about the concept of agency among people with dementia and thus expand on the vision of Nolan [60] and others toward a more inclusive model of PwD. This is a very challenging but necessary task which is pressing given the continuously rising rate of PwD in an aging society.

The health care system at all levels of its practice and education including CME could contribute to creating a formative culture of caring for dementia that is informed by evidence currently in need of enrichment.

These efforts are a call to action and, such efforts have already begun. GAP (Global Action on Personhood) in Dementia is an informal international network of expert practitioners, researchers, educators, people living with dementia and family care-givers who have in-depth understanding of person-centered

Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 9 of 10

approaches to care world-wide, [61]; Global alliances that aim to facilitate person centered care in dementia include World health organization [62]. We hope that more multidisciplinary team research in this area will follow in the future.

Availability of data and materials
The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Authors' contributions
RB and CT designed and implemented the research as well as analyzed the data and wrote the paper. KM assisted with the analysis of the data and writing the paper. All authors read and approved the final manuscript.

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R.B. is a gerontologist and a trained bereavement counselor. She has over 30 years experience working with people with dementia.
C.T. is a medical doctor, and director of Melabev's Research Department.
K.M. is an Associate professor at Hadassah Academic College Jerusalem. She is a medical anthropologist.

Ethics approval and consent to participate
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Consent for publication
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Competing interests
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Berenbaum *et al. Journal of Compassionate Health Care* (2017) 4:8

Page 10 of 10

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