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What affects pleasure in persons with advanced stage dementia?

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Abstract

We examined the impact of environmental, person, and stimulus characteristics on pleasure in persons with dementia. Study participants were 193 residents of 7 Maryland nursing homes who were presented with 25 stimuli from these categories: live human social stimuli, simulated social stimuli, inanimate social stimuli, a reading stimulus, manipulative stimuli, a music stimulus, task and work-related stimuli, and two different self-identity stimuli. Systematic observations of pleasure in the natural environment were conducted using Lawton's Modified Behavior Stream. Analysis showed that pleasure is related to stimulus category, personal attributes and environmental conditions. In the multivariate analyses, all types of social stimuli (live and simulated, human and nonhuman), self-identity stimuli, and music were related to significantly higher levels of pleasure than the control condition. Females and persons with higher ADL and communication functional status exhibited more pleasure. Pleasure was most likely to occur in environments with moderate noise levels. These results demonstrate that these nursing home residents are indeed capable of showing pleasure. Caregivers of nursing home residents with dementia should incorporate social, self-identity, and music stimuli into their residents' care plans so that eliciting pleasure from each resident becomes the norm rather than a random occurrence.

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Keywords

nursing home residents with dementia; pleasure; environment; personal characteristics; nonpharmacological intervention

The study of pleasure in person with dementia has been limited to demonstration of the impact of activity or stimuli on pleasure. The positive impact of engagement with stimuli or activities on the affect of nursing home residents with dementia has been reported (Beck et al., 2002; Engelman et al., 1999; Orsulic-Jeras et al., 2000; Bowlby-Sifton, 2001; Libin & Cohen-Mansfield, 2004; Cohen-Mansfield et al., 2007; Cohen-Mansfield et al., 2011; Kolanowski et al., 2002; Mausbach et al., 2008; Moore et al., 2007; Williams & Tappen, 2007; Meeks et al.,2007; Meeks et al., 2008). For instance, Moore et al. (2007) presented a variety of engagement activities to 3 nursing home residents and found that their levels of happiness increased with every activity presented. Interaction with a robotic cat yielded a significant increase in pleasure and interest in 9 female nursing home residents with dementia (Libin & Cohen-Mansfield, 2004). Orsulic-Jeras et al. (2000) demonstrated that individualized nonpharmacologic interventions resulted in more pleasure and constructive engagement and less negative affect than the usual programmed activities in the nursing home. In another study which utilized individualized nonpharmacological interventions, significant increases in pleasure and interest as well as decreased agitation were found for167 nursing home residents with dementia (Cohen-Mansfield et al., 2007).

In addition to data from nursing home residents, a few studies have looked at the role played by stimuli or activities on pleasure in community-dwelling persons with dementia. Analysis of data from 12 adult day center (ADC) attendees who participated in an art program intervention designed specifically for persons with early to middle stages of dementia revealed that these persons showed significantly more pleasure as well as interest and attention during this art program than during traditional ADC activities (e.g., current events, crafts) (Kinney & Rentz, 2005). Additionally, a home-based program of individualized occupational therapy interventions administered by family caregivers was shown to enhance pleasure (98%) as well as engagement (100%) for persons with dementia (Gitlin et al., 2009).

Recently, observed affect was systematically assessed in nursing home residents with dementia and analysis revealed that pleasure was highest for live social stimuli (e.g., 1-on-1 human interaction), followed by individualized stimuli (based on the participant's self-identity) and simulated social stimuli (e.g., a robotic animal); the lowest level of pleasure was observed for building blocks (Cohen-Mansfield et al., 2011). Overall, residents with comparatively higher cognitive function (MMSE ≥ 10) had significantly greater pleasure than those with lower cognitive function (MMSE < 3). As pleasure is a salient but under-researched indicator of quality of life in nursing home residents with dementia, we have extended this research beyond stimulus attributes and present the combined impact of personal attributes (e.g., sex, ADL performance) and environmental conditions (e.g., lighting, length of stimulus presentation) on pleasure.

Methods

Participants

In this study of nursing home residents, our inclusion criterion was a diagnosis of dementia. Exclusion criteria were: an accompanying diagnosis of bipolar disorder or schizophrenia, a lack of dexterity or movement in either hand, unable to be seated comfortably in a chair/ wheelchair, a MMSE score above 23, or younger than 60 years. Study participants were 193

residents from 7 Maryland nursing homes. Of these, 78% were female and age averaged 86 years, ranging from 60 to 101 years. The majority of participants was Caucasian (81%), and most were widowed (65%). ADL performance, which was obtained through the Minimum Data Set(Morris et al., 1991), averaged 3.6 (SD 1.0, range 1-5; Scale: 1 - 'complete dependence' to 5 - 'independent'). Cognitive functioning, as assessed via the Mini-Mental State Examination (Folstein et al., 1975), averaged 7.2 (SD 6.3, range 0-23). Participants had an average of 6.7 medical diagnoses.

Procedure

The study received IRB approval. Informed consent was obtained from either the participant (n = 2) or from a relative or other responsible party (n = 191) (Cohen-Mansfield et al., 1988). Participants' assent to participate was respected throughout the study. Whenever a participant refused a stimulus (verbally and/or behaviorally) or showed discomfort with any of the study procedures, the research staff withdrew. Each of 25 predetermined engagement stimuli were presented to participants over a three-week period (approximately 4 stimuli per day). Stimuli were usually presented in the activity room, but sometimes at other locations, such as the dining room. Stimuli were from these categories: live human social stimuli, simulated social stimuli, inanimate social stimuli, a real dog, a reading stimulus, manipulative stimuli, a music stimulus, task and work-related stimuli, and two different personalized stimuli that were based on the study participant's self-identity. We matched the choice of music to the background of the person such that the music stimulus included classical, gospel, Yiddish, and Persian music.

As to stimulus presentation, one research assistant presented each stimulus to a study participant and a second research assistant, who remained unobtrusive, observed the participant's pleasure, entering the data directly onto a handheld computer (Palm One Zire 31™). Stimuli were presented in random order with either a long introduction with modeling or a short, minimal introduction. If the participant refused the engagement stimulus, the research assistant removed it. Stimuli were presented between 9:30 am – 12:30 pm and between 2 pm – 5:30 pm, as these are the times that residents are not usually occupied with care activities at the nursing homes. For each observation, pleasure was measured during the first 3 minutes after the stimulus was presented. Stimuli were separated by a washout period of at least 5 minutes, as our experience has shown that a 5 minute wash-out period is sufficient for the population under study. In the present study, the wash-out period was often longer than 5 minutes. In addition, participants were observed when no stimuli were presented (i.e., control observations).

Dependent variable—As it is often impossible to elicit self-report from persons with advanced dementia, pleasure was observed using Lawton's Modified Behavior Stream (Lawton et al., 1996). Pleasure was noted when the participant smiled, laughed, or showed other outward manifestation of happiness and was quantified using this 5-point scale: (1) Never, (2) < 16 seconds, (3) < half of the observation, (4) more than half, and (5) all or nearly all of the observation (Lawton et al., 1996). The calculation of inter-rater agreement for the assessment of pleasure yielded an ICC of 0.71 and an agreement rate of 90%.

Independent variables

Environmental attributes

Setting and presentation: Background noise, lighting, and the number of persons in proximity were obtained via the environment portion of the Agitation Behavior Mapping Instrument (Cohen-Mansfield et al., 1989). Background noise was recorded as: 1=none, 2=low, 3=moderate, 4=high, 5=very high. Lighting was recorded as 1=bright, 2=normal, 3=dark. Number of persons in the vicinity (i.e., number of persons in the room; when the

participant was in the corridor, we included the number of persons in about half the length of the corridor) of the participant was recorded as: 1=zero, 2=one person, 3=two persons, 4=three persons, 5=from four to nine persons, 6=from ten to twenty-four persons, 7=twenty-five or more persons.

Modeling: Each stimulus was presented twice during the study (but never on the same day), once with an explanation and demonstration of how the stimulus should be used, and once without such modeling.

Personal Attributes: Demographic and medical data were retrieved from the residents' charts at the nursing homes, including information about sex, age, marital status, ethnicity, education, current medications (including psychotropic drugs), and medical diagnoses (including depression). Data assessed using the MDS (Morris et al., 1991) included: activities of daily living (ADL; a mean was calculated for each participant from 10 items pertaining to bed mobility, transferring, locomotion on the unit, dressing, eating, toilet use, personal hygiene, bathing, bladder incontinence, and bowel incontinence – each rated from 1= maximum dependence to 5); speech clarity (1=no speech, 2=unclear speech, 3=clear speech); making oneself understood (1=rarely/never understood, 2=sometimes understood, 3=usually understood, 4=understood); vision (recorded on a 5-point scale where 1=severely impaired, 5=adequate); and hearing (4-point scale where 1=highly impaired, 4=hears adequately). The MMSE (Folstein et al., 1975) was administered to each participant by a research assistant trained with regard to standardized administration and scoring procedures. In order to determine activities of interest to the participant, we interviewed the resident whenever possible and also conducted a telephone interview with a close relative using the Self-Identity Questionnaire(Cohen-Mansfield et al., 2006). The SIQ examines four types of role-identity: professional, family-role, leisure activities, and personal attributes. We calculated the number of leisure activities that had been named as a past interest for each study participant.

Stimulus attributes: The stimuli were categorized according to the stimulus attributes of: *live human social stimuli*, which included a real baby and one-on-one socializing with a research assistant; *simulated social stimuli*, which included a life-like (“real”) baby doll, a robotic animal, and a respite video (a commercially available video of a person talking to the person with dementia; the video often includes singing and asking the viewer to join in (Hall & Hare,1997; Lund et al., 1995); *inanimate social stimuli* which included a childish-looking doll and a plush animal; *a real* pet which involved visits with a real dog, a *reading stimulus*, which included a large print magazine; *manipulative stimuli*, which included a squeeze ball, tetherball, expanding sphere, activity pillow, building blocks, a fabric book, a wallet (males) or purse (females), and a puzzle; *a music stimulus*, which included listening to recorded music; *task and work-related stimuli*, including arranging flowers, coloring with markers, stamping envelopes, folding towels, and an envelope sorting task; and two different personalized stimuli, based on the study participant's *self-identity*. The self-identity stimuli were matched to each participant's past identity with respect to occupation, hobbies, or interests. For example, an individual with an interest in astronomy could be given a book on stargazing and constellations, and a participant who worked as a chef might watch cooking videos. Self-identity stimuli therefore varied across participants.

Statistical methods—In order to use both observation level variables and person level variables, we developed a proportional odds model with repeated measurements for the different stimuli using Generalized Estimating Equations (GEE), executed by the Genmod Procedure (Liang & Zeger, 1986) with the option “Repeated” in SAS (version 9.13), assuming a multinomial distribution for the outcome variables and the cumulative logit link.

The GEE approach allows us to examine the effects of different stimuli within the same model, taking into account the within-person correlations between the outcomes following each stimulus. The explanatory variables were: type of stimulus (10 nominal categories); the personal attributes of: age, sex, marital status, ethnicity, education, number of diagnoses, number of medications, number of psychotropic medications, MMSE, ADL, clarity of speech, number of past interest, vision, and hearing; and the environmental attributes of: introduction (long vs. short), sound, lighting, and number of people present.

The process of building the multivariate model started with fitting a univariate model. Explanatory variables that were significant at a probability of at least 0.20 were entered into a backward elimination procedure in which the least significant variables were eliminated sequentially until all remaining variables were significant at the 0.05 level. This constituted the final multivariate model. Prior to the analysis, we compared the different nursing homes on level of pleasure across all conditions using analyses of variance (ANOVA), and found that pleasure did not differ across the nursing homes. Therefore nursing home was not included in the main analysis.

Results

Table 1 provides mean levels for pleasure for the different stimuli. Findings from the GEE univariate analyses are presented in Table 2. Significant relationships were found with stimulus attributes, personal attributes, and environmental attributes. Specifically, the following stimulus categories yielded significant increases of pleasure as compared to the control/no stimulus condition (organized by the odds ratio): live human social, pet, simulated social, stimuli related to self-identity, inanimate social, and music. As to personal attributes, study participants who were more likely to display pleasure were female, not married, had comparatively higher levels of cognitive function and ADL function, and demonstrated clear speech. As to environmental influences, a longer introduction with modeling, a moderate level of sound, a normal light level, and 2-3 persons in the social environment were significantly related to higher levels of pleasure.

The results of multivariate analysis (see Table 3) revealed that all three types of attributes, i.e., stimulus, person, and environment, significantly influenced pleasure. For stimulus attributes, the 4 categories of social stimuli significantly increased pleasure (in the same order as the odds ratio found in the univariate analyses, i.e., live human social, real pet, simulated social, and inanimate social). Additionally, self-identity stimuli and music stimuli had a significant impact on pleasure. The personal attributes of female gender, better ability to perform ADLs and clarity of speech independently predicted pleasure, and the environmental attribute of sound, specifically a moderate level of sound, was associated with higher levels of pleasure.

Discussion

This paper is the first to show that a combination of personal factors, environmental attributes and stimulus characteristics impact levels of pleasure in nursing home residents with dementia. We have demonstrated, in the multivariate as well as univariate analyses, that any type of social stimulus has a significant impact on pleasure. We believe this result is most likely due to the deep loneliness and isolation experienced by nursing home residents. This result provides hope for ameliorating their loneliness and isolation as even inanimate social stimuli were found to be significantly preferable to the control condition. While 1-on-1 live human interaction was indeed the most potent stimulus, many alternatives, including pets and simulated social stimuli had a highly significant impact, leading us to suggest that these interventions be used routinely with this population.

Several stimulus categories did not result in significantly increased pleasure, namely manipulative stimuli (e.g., blocks), reading, and task/work stimuli (e.g., folding towels). While those stimuli have been shown to engage persons with dementia (Cohen-Mansfield et al., 2010) and thus may be useful activities for persons with dementia who are unable to engage themselves, those stimulus categories do not seem beneficial for enhancing positive affect in this population.

We are not sure why women displayed more pleasure than men. It may be the case that females are more likely to show emotion. Future research needs to explore this, and alternative explanations focusing on the different circumstances of men and women in the nursing home (e.g., men tend to be married, whereas women are widowed.)

Sex was not the only personal attribute contributing to pleasure in the multivariate analysis as we found that pleasure increased with higher functional status (exhibited by ADL and by clarity of speech), suggesting that the exhibition of pleasure is more similar to a functional state than to a cognitive state. That is, the ability to experience or display pleasure may be thought of as a skill that tends to get lost with the progression of dementia in a manner similar to the loss of other functional skills such as the ability to eat or walk. This suggests the possibility that the experience of pleasure might be maintained with continuous practice; conversely, pleasure may be more likely to be lost in dreary, unhappy, and boring environments. That needs to be examined in future research. An alternative explanation for the relationship of pleasure with functional status is that the observable affect assessment is not sufficiently sensitive to detect pleasure at more advanced stages of dementia.

The only environmental factor which remained significant in the multivariate analysis was that of moderate sound. This could be based on sound serving to alleviate a sense of loneliness, as when people leave the TV on as a background companion regardless of whether they actively pay attention to it. This finding may also reflect the relationship among the significant environmental variables, e.g., moderate sound is more likely when there are other persons around, as opposed to being alone in one's own room. The findings regarding environmental influences should be replicated using technologies to measure light, sound and temperature rather than relying on research staff's perceptions.

Overall, the observed levels of pleasure were low, yet we believe that the differences in pleasure are not only statistically meaningful, but also clinically. As we used only a 3 minute window of observation, even a fleeting sense of pleasure is noteworthy; particularly, if one considers that there are many 3 minute intervals during the day and that the sum of these fleeting moments can amount to meaningful moments of pleasure. Additionally, we believe that discreet occurrences of pleasure are meaningful, as people do not always outwardly display pleasure, such as in a smile.

The results of the present study serve as a first step for continued research in this area. For instance, the methodology reported here was selected to clarify aspects of environment, personal, and stimulus attributes affecting pleasure. Future research is needed to expand the concept and methodology so as to maximize clinical utility. The utilization of the GEE methodology allowed us to include many different types of influences simultaneously, including those that changed with each stimulus presentation (e.g., stimulus attributes) and those that remained constant (e.g., personal attributes). However, we were unable to include the even more complex issues of person–stimulus interactions. Future research should study potential person-stimulus interactions (e.g., do persons who once enjoyed music manifest more pleasure in response to music?), environment-person interactions (e.g., do persons who were once very social show more pleasure when around others, while solitary persons show more pleasure when alone?), and stimulus-environment interactions (i.e., is the impact of

certain stimuli greater in certain environments, while the impact of other stimuli is maximized in different environments?). The findings of factors affecting pleasure in persons with dementia should also be expanded in future research to include different populations or subpopulations and different settings.

The data have shown that the combined influence of person attributes, environmental attributes, and stimulus attributes impact pleasure in persons with dementia. As a major indicator of quality of life in end stages of dementia, pleasure needs to be increased in the nursing home population. This paper demonstrates that the use of appropriate stimuli is one important avenue to increase pleasure. Increased positive interaction with staff and volunteers during care activities or at other times is another crucial avenue. Finally, our suggestion that the experience of pleasurable moments is a functional skill that needs to be continually practiced by a nursing home resident with dementia if that person is to maintain the ability to experience pleasure should be further examined.

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Table 1
Mean levels of pleasure by type of stimulus category

Stimulus category	Pleasure (mean)
Live human social	1.94
Real pet	1.88
Simulated social	1.58
Self-identity	1.50
Inanimate social	1.40
Music	1.26
Manipulative	1.20
Task/work-related	1.19
Reading	1.18
Control condition	1.17

Table 2
Results of GEE univariate analyses relationships with pleasure

		Odds Ratio	Confidence interval	P
Stimulus attributes				
Type of stimulus				<0.0001
	Control	1.00		
	Live human social	8.66	5.71-13.13	<0.0001
	Real pet	6.72	4.28-10.55	<0.0001
	Simulated social	3.49	2.44-4.98	<0.0001
	Self-identity	2.78	1.90-4.05	<0.0001
	Inanimate social	2.49	1.74-3.57	<0.0001
	Music	1.62	1.06-2.49	0.027
	Manipulative	1.21	0.86-1.70	0.274
	Reading	1.03	0.63-1.69	0.903
	Task/work-related	1.01	0.71-1.43	0.972
Personal attributes				
Sex	Male	1.00		
	Female	1.72	1.14-2.59	0.007
Marital status	Other than married	1.00		
	Married	0.64	0.45-0.91	0.012
Number of diagnoses				0.236
	<=5	1.0		
	5-7	1.39	0.95-2.04	0.086
	>7	1.19	0.81-1.76	0.382
MMSE				**0.002**
	<3	1.00		
	3-10	1.52	1.00-2.30	0.048
	>= 10	2.09	1.40-3.13	0.0003
ADL				**0.0003**
	<=1.6	1.00		
	1.6-2.9	2.09	1.44-3.04	0.0001
	>2.9	1.84	1.26-2.69	0.0016
Clarity of speech				**0.0001**
	Clear speech	1.00		
	Unclear speech	0.51	0.37-0.71	<0.0001
	No speech	0.06	0.01-0.31	0.0006
Vision				0.394
	Adequate	1.00		
	Impaired	1.00	0.72-1.40	0.989
	Moderately impaired	0.89	0.53-1.48	0.645
	Highly impaired	0.62	0.36-1.05	0.075

		Odds Ratio	Confidence interval	P
Environmental attributes				
Introduction	Short	1.00		
	Long	1.34	1.21-1.48	<0.0001
Sound				**<0.0001**
	None	1.00		
	Low	4.27	0.59-30.83	0.150
	Moderate	6.19	0.88-43.55	0.067
	High	3.67	0.50-27.07	0.203
Lighting				**0.0303**
	Normal	1.00		
	Bright	0.60	0.39-0.90	0.014
	Dark	0.74	0.46-1.20	0.224
Number of persons around				**0.012**
	0	1.00		
	1	1.12	0.82-1.54	0.473
	2	1.95	1.35-2.81	0.0004
	3	1.70	1.14-2.54	0.009
	4-9	1.36	0.98-1.90	0.065
	10-24	1.42	1.04-1.95	0.028
	25+	1.08	0.63-1.84	0.780

Note: The personal attributes of: age, ethnicity, education, number of past interests, number of medications, number of psychotropic medications, and depression diagnoses did not reach a P-value under .2.

Note: *Live human social stimuli* included a real baby and 1-on-1 socializing with a research assistant; *simulated social stimuli* included a life-like ("real") baby doll, a robotic animal, and a respite video; *inanimate social stimuli* included a childish-looking baby doll and a plush animal.

P-values are based on Wald statistics with 1 degree of freedom for individual categories, and with k-1 degrees of freedom for the overall test of a variable with k categories.

P-values under .2 are bolded and those variables were included in the multivariate model. In the Odds Ratio column, the reference value for each variable = 1.00

Table 3
Results of GEE multivariate analyses –variables explaining pleasure

		Odds ratio	Confidence interval
Type of stimulus	Control condition	1.00	---
	Live human social	9.30***	6.14-14.08
	Real pet	7.46***	4.71-11.82
	Simulated social	3.81***	2.65-5.48
	Self-identity	3.05***	2.07-4.50
	Inanimate social	2.69***	1.87-3.88
	Music	1.74*	1.12-2.71
	Manipulative	1.26	0.89-1.79
	Reading	1.10	0.66-1.83
	Task/work-related	1.04	0.72-1.49
Sex	Male	1.00	---
	Female	1.72**	1.15-2.57
ADL	<=1.6	1.00	---
	1.6-2.9	2.00***	1.38-1.90
	>2.9 higher function	1.71**	1.17-2.52
Clarity of speech	Clear speech	1.00	---
	Unclear speech	0.56***	0.40-0.77
	No speech	0.06**	0.01-0.40
Sound	None or Low	1.00	
	Moderate	1.50**	1.15-1.96
	High	0.90	0.56-1.43

* $p \leq .05$;

** $p \leq .01$;

*** $p \leq .001$

The following were not candidates for the multivariate analysis since these were not significant (P<0.2) in the univariate model: age, ethnicity, education, number of diagnoses, depression, number of past interests, vision, hearing, number of medications, number of psychotropic medications.

The following variables entered the backward elimination procedure and were excluded from the final model due to non-significance: Introduction, marital status, MMSE, lighting, social environment.