2007

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Concordance of Self-Report and Informant Assessment of Emotional Well-Being in Nursing Home Residents With Dementia

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Received December 21, 2005; accepted June 28, 2006. Decision Editor: Thomas M. Hess, PhD.

The emotional well-being of persons with dementia is an aspect of their quality of life. We examined the stability of informant-rated and self-reported emotion, and the influence of mental status and physical dependence on ratings; we modeled concordance between ratings at both the within- and between-person levels of analysis. We used multilevel modeling to examine data collected over 12 days from 31 nursing home residents. We found significant within-person variation in both informant-rated and self-reported emotion, such that between 40% and 60% of the overall variance in each occurred within persons. We found little correspondence between or within persons between ratings of the informants and residents, regardless of mental status. We recommend statistical techniques that describe these high levels of daily variation in persons with dementia.

The emotional well-being of persons with dementia (PWD) is an important aspect of their quality of life (Lawton, Van Haitsma, Perkinson & Ruckdeschel, 1999). As researchers, we are just beginning to understand the emotional responses that characterize PWD and how to measure them. For the most part, the literature describes informant reports of negative components of emotionality and documents variability in emotional reactivity between individuals. In this study we take a broader perspective of emotionality that includes both positive and negative aspects of emotion, and we use modern analytical techniques to capture a more complete description of well-being in nursing home residents with dementia. Specifically, we examine the stability of measures of emotional well-being by using statistical models that address both interindividual differences (i.e., a between-person model) and intraindividual change or variation over time (i.e., a within-person model). In addition to stability, we examine the concordance between informant ratings and residents' self-ratings of emotional well-being.

Much of what we know about emotional well-being comes from studies of the general population, and this knowledge is informative for our purposes. There is consensus that emotional well-being consists of both positive and negative affect (Charles, Reynolds & Gatz, 2001). It is well known that positive and negative affect are only modestly correlated (Carstensen, Pasupathi, Mayr & Nesselroade, 2000; Watson, Clark & Tellegen, 1988), so well-being is best understood as the balance between these two constructs. Although negative emotions are quite common in dementia (Galyner, Roane, Miner, Feinberg & Watts, 1995), PWD also display positive emotion, even through the late stages of dementia (Albert et al., 2001; Magai, Cohen, Gomberg, Malatesta & Culver, 1996). To our knowledge, only a few studies of PWD have been designed to measure positive emotion, so we know very little about this component of emotional well-being or the extent to which positive and negative emotion are dissociated in PWD. The literature also highlights an important distinction between average levels of affect and intraindividual variability in affect (Eid & Diener, 1999). Intraindividual variability, in contrast to average levels of affect, reflects reactivity to contextual factors and is essential for understanding emotional experiences over time. In general, greater inconsistency in response is typical of individuals with neurological disturbances (Strauss, MacDonald, Hunter, Moll, & Hultsch, 2002). Because of their memory impairments, PWD tend to live in the “here and now.” This change in temporal making daily fluctuations a very important indicator of their emotional wellbeing. In fact, intraindividual variability could arguably be one of the most important aspects of emotional well-being in PWD. To our knowledge, descriptions of intraindividual variability in the affective responses of PWD are not currently available; thus, our first goal in the current study is to examine the magnitude of daily, within-person variation in emotion relative to the between-person, interindividual variation that is found in PWD.

Daily reports of emotional well-being are a product of personality and contextual factors and may also be influenced by mental status and functional ability in PWD because of their known global effects on mental health (Feehan, Knight, & Partridge, 1991). There is good evidence that supports a relationship between declining mental and physical function and the expression of behavioral symptoms in PWD (Finkel, 2003). Indicators of mental and physical competence are likely to predict emotional well-being in PWD; thus, our second goal in the current study is to examine how these indicators predict both level and stability of emotion across days in PWD.

In the general population, emotional well-being is usually assessed by self-reports, observable displays of affect (Lawn-
not reflect the amount of daily variation experienced by individual residents, and recent work on the validity of mood indicators in the Minimum Data Set, for example, raises questions about informant data’s being used as a sole source of assessment in PWD (Hendrix, Sakauye, Karabatsos, & Daigle, 2003; Horgas & Margrett, 2001). Compounding this issue are findings that informant reports of emotional well-being often vary from each other, offering little convergence (Desbiens & Mueller-Rizner, 2000; Teri & Wagner, 1991). One source of bias that has been identified in reports of emotional well-being is the amount of subjective burden experienced by caregiving informants. Caregivers who report greater burden are also more likely to report lower emotional well-being in the care recipient than those with less perceived burden (Rosenberg, Mielke & Lyketsos, 2005).

Fortunately, there is growing interest in the subjective experiences of PWD (Cotrell & Hooker, 2005; Hubbard, Downs, & Tester, 2003). Findings indicated that PWD have a sense of self and their feelings, but that methods of exploring these experiences require further development. Examining the concordance between trained noncaregiver and resident ratings of emotional well-being in terms of both interindividual and intraindividual variability would add a dimension to the literature on the reliability of these reports. Thus, our third goal in the current study is to examine the reliability of ratings of emotion over time across both sources of assessment (i.e., informants vs residents) and dimensions of assessment (i.e., positive vs negative emotion).

In summary, our purpose in the current study is to examine several gaps in the literature on emotional well-being of nursing home residents with dementia. We examine the stability of informant-rated and self-reported positive and negative emotion, as well as the moderation by mental status and physical dependence on the relationships among these outcomes in PWD. Further, in this study we add to the literature on the accuracy of self-reported emotionality in PWD by using highly trained research assistants as informants for the assessment of observed emotion, and by using modern analytical techniques to examine the concordance between ratings of emotional well-being from multiple sources both within persons and between persons. We addressed the goals of this study by means of three research questions:

1. How stable is emotional well-being across a 12-day period within each resident (a) as rated by trained informants, and (b) as self-reported by the residents?
2. To what extent does level and stability across days of informant-rated and self-reported emotional well-being differ as a function of mental status and physical dependence?
3. To what extent are informant-rated and self-reported emotional well-being related (a) between persons and within persons, and (b) do these relationships differ as a function of mental status and physical dependence?

METHODS
Participants and Design
The study sample included 31 nursing home residents with dementia who were recruited from four nursing homes in central and northeast Pennsylvania and who met strict enrollment criteria: they were English speaking; had a diagnosis of dementia that met the criteria set forth in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994); had a Mini-Mental State Exam (MMSE; Folstein, Folstein & McHugh, 1975) score of 26 or less; had a stable dose of any psychoactive drug from prebaseline through final observation; and exhibited behavioral symptoms as reported by staff and documented in the subjects’ Minimum Data Sets. Exclusion criteria included having a history of psychiatric problems, alcoholism, diagnosis of Parkinson’s disease, or stroke; having a Hachinski score above 4 to rule out vascular dementia; having received a new psychoactive medication within the past 30 days; and having an acute illness. On average, the residents were female (n = 24), were 82.7 years old (SD = 7.7, range = 58-94), and had 11.0 years of education (SD = 2.5, range = 6-16), reflecting demographic characteristics that are typical of nursing home residents (Jones, 2002).

In this study we used baseline data from a crossover experimental study that tested the efficacy of three different treatment conditions for reducing agitation and passivity. We established the database for designing interventions that better address nursing home residents’ unique needs and characteristics related to emotional regulation. For this reason, we took multiple measures of emotional well-being during baseline and conditions to more fully capture participants’ patterns of emotional response. We have described the methodology in detail elsewhere (Kolanowski, Litaker & Buettner, 2005).

Briefly, a geriatric nurse practitioner screened consenting participants for mental status and physical dependency, using instruments with known reliability and validity. The geriatric nurse practitioner obtained data on demographics, medical diagnoses, including verification of dementia diagnosis using DSM-IV criteria, and prescribed medications by using a medical chart review. Following this screen, participants entered a 12-day baseline period. We chose this time frame because it represents a clinically meaningful period of time in which to assess emotional well-being in this population. During baseline, participants were observed and videotaped for 20 minutes each day at the time of day when they exhibited a high level of agitation or passivity as determined by nursing home staff report and observation. We selected these times to provide staff the opportunity to observe a spectrum of emotional responses. Before and after each 20-minute observation session, a trained research assistant used a standard instrument to ask participants about their emotional well-being. The assistant was blind to study aims. Measures of emotional well-being were taken from the videotapes by trained raters blind to study aims.

Research assistants and video raters were trained in a 2-day educational session designed to familiarize them with facial expressions and body postures of older adults, behavioral signs that indicate the presence of positive and negative emotions, and the instruments used for data collection. Video raters worked one on one with the Principal Investigator while watching videotapes of PWD. Whereas formal and informal caregivers often have knowledge of the resident’s normal pattern of emotional response, blinded raters are free of the reporting bias that comes from caregiver subjective burden (Rosenberg et al., 2005). Video raters were trained to focus on emotional responses in a context-free manner and achieved 80% agreement with the Principal Investigator before entering the field.
We measured physical dependence. We measured mental status by using the MMSE (Folstein et al., 1975). The MMSE contains items from seven domains of cognitive function: orientation, registration, attention, calculation, recall, language, and visual construction, in which each item has between two and five response options to each of no, yes, and very much. The frequency response in each category across persons and days for each item is given in Table 1.

We also estimated categorical factor models for these non-interval responses, in which the pictures of good mood and happy indicated a latent factor of positive mood, and the pictures of bad mood, angry, sad, and worried indicated a latent factor of negative mood. We then estimated latent trait estimates from a constrained graded response model for further analysis. Given that the observation data analyzed in the current study were from a baseline condition in which no intervention was conducted, we used the mean of the latent trait estimates of the ratings before and after the 20-minute period (results were similar when we used the before or after ratings, however). We estimated the model-based reliability at 0.64 for both positive and negative emotion (two or four items, respectively).

Because of the noninterval nature of these response options, we opted not to use the sum scores directly in the analyses. Instead, we fit categorical factor models (i.e., graded response models; see Lawton et al., 1984) estimated in Mplus 3.1 (L. K. Muthén & Muthén, 1998-2004) to the responses across days and persons. The items for pleasure, interest, and contentment indicated a latent factor of positive affect, and the items of anger, anxiety, and depression indicated a latent factor of negative affect. We estimated latent trait estimates (i.e., Item Response Theory thetas) from a Rasch version of the graded response model (i.e., in which factor loadings were constrained equal across items) for further analysis. By using latent traits as the outcome measure instead of the sum or mean across items, we eliminate measurement error from the daily responses and we better account for the noninterval nature of the response options. We estimated within-day model-based reliability (Raykov, 1997) at 0.61 for both positive and negative emotion (two or four items, respectively).

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We measured self-reported emotional well-being. We measured self-reported emotional well-being in real time by using the Dementia Mood Picture Test (Tappen & Barry, 1995), an instrument that measures both positive and negative emotions from the perspective of the cognitively impaired participant. This instrument has previously demonstrated high inter-rater reliability (Intraclass correlations = 0.95-0.99). We had measures taken immediately before and after each observation period. An assistant showed each partici-
Self-reported emotional well-being. —The intraclass correlations for self-reported positive emotion and negative emotion were 0.54 and 0.59, respectively, indicating that within-person variation across the 12 days was almost as large as between-person variation. The average correlation across days was 0.54 for self-reported positive emotion and 0.59 for negative emotion. Observed trajectories across the 12 days for each respondent in self-reported positive and negative emotion are shown in top and bottom of Figure 2, respectively.

Informant-rated emotional well-being. —We examined stability across the 12 days in informant-rated positive and negative emotional well-being by means of intraclass correlations from an empty univariate multilevel model. The intraclass correlation is calculated as the proportion of total variance that is between persons (i.e., random intercept variance/total variance). The intraclass correlations for rated positive emotion and rated negative emotion were 0.61 and 0.39, respectively. Thus, for positive emotion the majority of the variance was between persons, whereas for negative emotion the majority of the variance was within persons. This indicates that day-to-day ratings fluctuated more for negative emotion than for positive emotion. The average correlation across days was 0.61 for rated positive emotion and 0.39 for rated negative emotion. Observed trajectories across the 12 days for each respondent in informant-rated positive and negative emotion are shown in top and bottom of Figure 1, respectively.

Stability of Emotional Well-Being

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Individual Differences in Level and Stability of Emotional Well-Being

Informant-rated emotional well-being. —We then examined the extent to which level and stability of informant-rated emotional well-being were related to individual differences in mental status (as measured by the MMSE) and physical dependence (as measured by the PGDRS) in separate mod-
els for each predictor and each outcome. We included each predictor as a fixed effect (i.e., as a predictor of between-person differences) and also in a log-linear model for the residual variance (i.e., as a predictor of the magnitude of within-person variation).

For informant-rated positive emotion, we found no significant effects of the MMSE and PGDRS scores on the between-person means or residual variances, indicating that overall level and magnitude of within-person variation in informant-rated positive emotion were not related to mental functioning or physical dependence. For informant-rated negative emotion, however, we found significant negative effects of the MMSE score on the between-person means and on the residual variance, such that persons of greater mental functioning showed lower levels of overall informant-negative emotion and less within-person variation in negative emotion.

Self-reported emotional well-being. — For self-reported positive emotion, the effect of MMSE score on the between-person means was not significant, but we did find a significant negative effect on the residual variance, such that although the overall level of positive emotion was not related to mental status, persons with greater mental status reported less within-person variation in positive emotion. The PGDRS score had significant positive effect on the between-person means and on the residual variance, such that persons of lesser physical dependence reported higher levels of overall positive emotion and less within-person variation in positive emotion. For self-reported negative emotion, we found a significant negative effect of MMSE score on the between-person means and on the residual variance, such that persons with greater mental status reported lower levels of overall negative emotion and less within-person variation in negative emotion. For self-reported negative emotion, we found a significant negative effect of MMSE score on the between-person means and on the residual variance, such that persons with greater mental status reported lower levels of overall negative emotion and less within-person variation in negative mood emotion. There was also a significant positive effect of PGDRS score on the between-person means and on the residual variance, such that persons with lesser physical dependence reported lower levels of overall negative emotion and less within-person variation in negative emotion.

Relations of Informant-Rated and Self-Reported Emotion

Between-person and within-person relations of rated and self-reported emotional well-being. — We estimated empty multivariate multilevel models in order to examine the between-person and within-person correlations simultaneously among informant-rated and self-reported positive and negative emotion. There were significant negative correlations between informant-rated positive emotion and negative emotion (between-person \( r = -0.66, p < 0.01 \)); within-person \( r = -0.55, p < 0.01 \), and between self-reported positive emotion and negative emotion (between-person \( r = -0.61, p < 0.01 \)); within-person \( r = -0.53, p < 0.01 \). This suggests that raters and residents were each internally consistent at the between-person, individual level, as well as at the within-person, day level. For example, residents who were rated or self-reported high in overall positive emotion (relative to the rest of the individuals in the sample) were also rated or self-reported low in overall negative emotion (relative to the rest of the sample). Similarly, on days when a resident was high on positive emotion (relative to herself or himself), she or he was also low in negative emotion (relative to herself or himself).

Correspondence between informant ratings and self-reported responses within each of the positive and negative dimensions of emotion was not as strong, however. Informant-rated positive emotion and self-reported positive emotion were not significantly correlated (between-person \( r = 0.30, p = 0.13 \)); within-person \( r = 0.05, p = 0.37 \), indicating that overall levels (between persons) and daily levels (within persons) of positive emotion were not related across sources. Informant-rated negative emotion and self-reported negative emotion were not significantly correlated between persons (between-person \( r = 0.30, p = 0.15 \)) but were significantly correlated within persons (within-person \( r = 0.17, p < 0.01 \)) indicating that although overall levels of negative emotion were not related between persons, daily levels of negative emotion were related within persons. Although in the current sample of 31 persons the statistical power to detect a between-person correlation of 0.30 was less than 0.50, a correlation of 0.30 would not indicate acceptable reliability, regardless of statistical significance.

Individual differences in covariation of informant-rated and self-reported emotion. — We then examined the extent to which the expected negative relationship between positive and negative emotion within the informants and within the residents differed as a function of mental status and physical dependence by including emotion as a time-varying (i.e., daily) predictor in univariate multilevel models (i.e., as estimated for Research Question 2). We separated each time-varying predictor into two variables: the person’s mean across days, representing between-person variation, and the person’s deviation about his or her mean, representing within-person variation. Significant effects of between-person predictors would indicate that overall levels of the predictor and the outcome are related, whereas significant effects of within-person predictors would indicate that daily levels of the predictor and outcome are related. We thus included MMSE and PGDRS scores as main effects and as interactions with the between-person and within-person predictors of emotion in order to examine the extent to which the magnitude of covariation was moderated by mental status or physical dependence.

In the model predicting informant-rated positive emotion from informant-rated negative emotion, both the between-person and within-person effects of negative emotion were significantly negative; we also found a significant underadditive interaction between them, such that the within-person effect of negative emotion was reduced with greater between-person negative emotion. There were significant interactions of MMSE score and of PGDRS score with between-person negative emotion, such that the between-person effect became stronger (i.e., more negative) with higher MMSE scores or lower PGDRS scores. In other words, the correspondence between overall levels of rated positive and negative emotion was stronger in persons with higher mental status or lesser physical dependence.

In the model predicting self-reported positive emotion from self-reported negative emotion, the between-person
and within-person effects of negative emotion were significantly negative, although their interaction was not significant. MMSE score had significant interactions with between-person and within-person negative emotion, such that the effects of each were stronger (i.e., more negative) with higher MMSE scores. Figure 3 shows the predicted within-person relationship between self-reported negative and positive emotion (i.e., the relationship between daily fluctuation in each relative to one’s own average) for prototypical individuals with either low or high mental status (MMSE = 4 or 12) and low or high overall negative emotion (± SD). The slope of the lines thus represents the strength of the within-person relationship, and the relative distance between the lines represents the between-person relationship. As shown in Figure 3, correspondence between both overall levels and daily levels of self-reported positive and negative emotion was stronger in persons with greater mental status. We found no significant interactions for PGDRS score.

No interactions with MMSE or PGDRS scores were significant when we were predicting informant-rated positive emotion from self-reported positive emotion, or informant-rated negative emotion from self-reported negative emotion, indicating that the between-person and within-person covariation across assessment methods did not relate to mental status or physical dependence.

DISCUSSION

Our purpose in the current study was to examine relationships at the between- and within-person levels among positive and negative emotion as rated by informants and as self-reported by 31 frail nursing home residents over a 12-day period. Despite the somewhat small sample size, several important results were found and can be summarized as follows. First, we found significant within-person variation in both informant-rated and self-reported positive and negative emotion, such that between 40% and 60% of the overall variance in each occurred within persons, across days. Second, persons of greater mental status or lesser physical dependence reported lower levels of negative emotion and greater stability of both positive and negative emotion. Finally, internal consistency of positive and negative emotion was stronger in persons of greater mental status, but we found little correspondence between or within persons between emotion ratings of the informants and residents, regardless of mental status. Implications of these findings are subsequently discussed here.

There is consistent evidence for the stability of positive and negative emotion in the general population (Diener & Larsen, 1984; Segerstrom, Taylor, Kemeny & Fahey, 1998). In one study, stability coefficients over a 12-day period reached .80 for positive emotion and .70 for negative emotion (Epstein, 1979). In our sample, the stability coefficients were lower. Informant ratings indicated that residents exhibited relatively more stability in positive emotion, whereas negative emotion showed more variation from day to day. This finding suggests that positive emotion may be governed by individual differences, whereas negative emotion may be more contextually driven. The idea that positive emotion may be “hard wired” is consistent with recent work by Almeida, Mrozek and Neupert (2004) and is supported by Albert and colleagues (2001), who found that positive affect and psychiatric symptoms were not related in patients with dementia. The relative stability of positive emotion coupled with the high variability of negative emotion in frail nursing home residents is an important finding, because it illustrates the need to further investigate emotion regulation in PWD and the genetic and environmental factors that may govern it.

Neither mental status nor physical dependency was related to overall level or daily variation in positive emotion, but both of them were related to negative emotion. Residents with greater dementia severity (i.e., lower mental status and higher dependency) displayed higher levels of and greater variability in negative emotion. High variability in negative emotion is characteristic of psychopathology. Lawton, Parmelee, Katz and Nesselroade (1996), for example, found greater variability in negative emotion for depressed older adults living in residential care compared with nondepressed older adults. Depressed individuals also displayed lower levels of and less variability in positive emotion. One of the consequences of dementia is that people become more susceptible to the negative influences of the environment, which in the nursing home are often intermittent but significant, such as change of shift activity and noise. Environmental challenges may be the source of the observed variation in negative emotion. Because of this variation, our findings underscore the need for intense measurement designs that reliably capture negative emotion in frail nursing home residents. Additionally, caregivers to PWD should pay particular attention to environmental triggers that may precipitate negative emotions. Simple environmental manipulations could reduce the need for many of the antipsychotic drugs used in the treatment of behavioral symptoms.

We found that residents’ self-reports of emotion demonstrated as much between-person difference as within-person.
son variability. Like informant ratings, there was no relationship between mental status and level of self-reported positive emotion, but persons with higher mental status had less daily variability in positive emotion. Dependency, in contrast, was related to both level of and daily variation in positive emotion. Factors that influence emotional well-being may be quite different from the resident’s perspective than from the informant’s perspective. Changes in functional ability are typical of later stages of dementia and necessitate many occasions when caregivers assist with personal care, reminding residents of their dependency and often eliciting negative responses. Our findings are similar to those of Logsdon, Gibbons, McCurry & Teri, (2002), who reported that functional impairment was related to lower self-reported quality of life in participants with the lowest cognitive functioning in their sample. Together these findings emphasize the important role that promotion of physical function could play in residents’ sense of well-being.

Not surprisingly, we found that informants, but also residents, were relatively internally consistent in reporting emotionality overall and at the daily level. Consistency improved with higher mental status and lesser physical dependency. The finding of consistency in the responses of cognitively impaired persons has been reported by others (Simmons et al., 1997; Snow et al., 2005), and it supports the reliability of resident self-reports. Our findings go beyond those obtained with measures from a single point in time, and they indicate that residents maintain internal consistency over time. Given this evidence and the lack of concordance between raters, we think that informant reports should not be substituted for resident reports of well-being.

Despite internal consistency in reports, we found no correspondence between the reports of residents and informants for positive emotion, and only weak correspondence for negative emotion at the daily level. Logsdon and colleagues (2002) obtained similar results in their sample of persons with mild to moderate dementia. Even though persons with MMSE scores of 10 and higher could give valid responses to a Quality of Life Questionnaire formatted with 13 items and four choices, there was little agreement between patients’ and caregivers’ responses. The participants in our sample were more impaired than theirs, but the instrument we used (the Dementia Mood Picture Test) was designed to elicit simple “yes” and “no” responses appropriate for moderate to severely impaired residents. A number of factors may explain our findings.

Obviously, there is no way to determine if observable displays of emotion actually mirror internal states in PWD. In fact, both intact persons and those with dementia display primarily neutral facial expressions that give no indication of emotional well-being (Volicer et al., 1999). Lawton, Van Haitsma and Klapper (1996) found that interest and contentment were the most frequently observed affects in their sample of nursing home residents (data consistent with ours), and displays of positive affect were seen less frequently than in the general population. Because facial expressions of emotion are low-frequency behaviors, even the very modest correlation we found between informant-rated and self-reported negative emotion is noteworthy. At the very least, residents’ reports of emotional wellbeing should be used to evaluate care.

Informants did not report the variability in positive emotion that residents did. Because positive emotions are socially acceptable, there are data to suggest that they may not be monitored as closely as negative emotions (Spain, Eaton, & Funder, 2000). That informants may “miss” displays of positive emotion in PWD has implication for staff training.

In summary, we found daily correspondence between resident and informant ratings to some extent for negative emotion but not for positive emotion. Mental status and physical dependence did not moderate this association. We did find overall and daily correspondence within observers, however, and internal consistency was indeed greater for residents with greater mental or physical functioning. On a more general note, the substantial degree of daily, within-person variability observed in both informant-rated and self-reported emotion highlights the importance of using intensive measurement designs through which such variation can be observed and statistical techniques (such as multilevel models) through which it can be properly described (e.g., Martin & Hofer, 2004; Nesselroade, 2001). Ignoring such variability may compromise findings within intervention studies and in other settings as well.

ACKNOWLEDGMENTS
This study was supported in part by a grant from the National Institute of Nursing Research (Grant R15NR08148) awarded to A. Kolanowski.

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