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Evidencing Kitwood's Personhood Strategies: Conversation as Care in Dementia

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The purpose of this chapter is to highlight the communication and language strategies involved in key positive care interactions identified by Kitwood (1997a) as central to affirming personhood of individuals with dementia. We focus upon the enactment of these strategies in the challenging environment of long-term care. In these facilities, residents typically are in the moderate or severe stages of dementia; staff are necessarily task-oriented; and very little knowledge is available about the residents prior to disease onset. Communication features of the positive care interactions are illustrated through transcript selections from recorded conversations in a long-term care facility with one individual in the moderate stage of dementia. As person-centered conversations lead to reciprocity, contributions on the part of the person with dementia are also shown. The real value of the examples of positive care interactions is that they reinforce the position that individuals with dementia, even those who are in the more advanced stages, retain communicative competence and are active contributors to interpersonal relationships. Moreover, the examples serve to debunk the myth that individuals with dementia in long-term care facilities are nonfunctioning, passive communicators.

Personhood and dementia

Personhood need not depend on the capabilities of the person with dementia or on our ability to overlook the person's impairments. According to Kitwood, personhood "is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust" (Kitwood 1997a: 8). His

definition acknowledges the interdependence and interconnectedness of human beings.

In the biomedical tradition, a well-established, but false, truism is that dementia results in the "loss of self." This reductionist viewpoint proposes that pieces of the self are lost when properties that constitute the person are lost, such as cognitive abilities or functional autonomy. Obstacles imposed by the broader social and physical environments also are important determinants of perceived disability and lessened quality of life for people living with impairment (Luborsky 1994). For example, clinical practitioners and researchers tend to rely on a proxy voice to describe these losses presumably because the "subject"/"victim" is no longer able to represent the "former self" (Sabat 2001). The dominating medical model of care for dementia can create and exacerbate excess disability through a discourse exclusively based on a deficit perspective emphasizing loss, victimization and spiraling declines.

Dementia is not always simply associated with decline and loss of function. There are also positive long-term changes. As the disease progresses, the potential for growth and contribution becomes more dependent on facilitation by others. Growth occurs in areas of coping skills, compensatory actions, creativity, spirituality, and in previously hidden areas of personality (see Kitwood 1997a; Ryan, Spykerman, & Anas, this volume). Freedom of expression and a release from previous constraints and concerns may present new sources of pleasure and satisfaction for the person with dementia. In our concerns for the tragedy of dementia and the suffering endured, we lose sight of the opportunities and the real, not just imagined, potential for the human spirit to emerge in the midst of undeniably difficult circumstances (Kitwood 1997a, b; Post, 2000).

Kitwood (1997a, b) provided a holistic view of the person who lives with impairment, a "survivor" who struggles to maintain his or her personal identity, his or her personhood as he or she is confronted with diminishing abilities. He called on caregivers of persons with dementia to return to the roots of care: to care for the person, not a disease. Kitwood and Bredin (1992) called for a change of culture in dementia care, away from the old perspectives permeated with its malignant social psychology, to a new culture where person-centered care is developed, embraced and practiced. At the core of person-centered care lies the principle that an individual's life experiences, unique personality, remaining strengths, and network of relationships must be recognized and valued (see also Harris 2002; Ronch & Goldfield 2003). The concept of personhood places a major responsibility on formal care providers as facilitators for

the person with dementia. While family caregivers are continually in a position to enhance personhood, the present chapter will highlight the usefulness and importance of personhood-affirming communication for formal care providers.

In Kitwood's view, the caregiver should act as facilitator for the person with dementia. Caregivers require both skills and attitude to relate to the "person" rather than the disease. The starting point for fulfilling this demanding and pivotal role, according to Kitwood and Bredin (1992), is in recognizing that the interaction is not between one party who is "damaged" and another who is whole and perfect. The person with dementia may be more vulnerable in some ways, but the caregiver also possesses weaknesses in at least some areas of functioning – perhaps on the interpersonal level, or with specific fears and uncertainties regarding impairment and death. The personhood of individuals with dementia is replenished continually through the generation and/or sustenance of interactions that are positive, stable, and secure. Such interactions meet five fundamental personal needs which overlap, coming together in the central need for love: comfort, attachment, inclusion, occupation, and identity (Kitwood 1997a).

Communication and dementia

Much research exists surrounding the language and communication difficulties experienced by individuals with dementia. Reports from caregivers about word-finding difficulties and socially inappropriate, repetitive or disruptive vocalizations (Hallberg *et al.* 1993) and empirical evidence (Kempler 1995; Ripich & Ziol 1998) reveal that lexical and pragmatic areas are largely affected. Individuals in the moderate to severe stages typical of residents in long-term care have a discourse that contains semantically empty phrases, incomplete sentences, paucity of ideas, reduced linkage between intent and wording, and lack of self-corrections (Bayles *et al.* 2000; Causino Lamar *et al.* 1994; Santo Pietro & Ostuni 2003). These deficits make it difficult for a listener, especially one who has not known the individual well, to follow the person's train of thought enough to keep up a satisfying conversation.

Consequently, conversing with an individual with dementia necessitates language and communication accommodations on the part of the interlocutor. Numerous individual language strategies have been suggested in addition to systematic attempts to train both family caregivers (see Byrne & Orange, this volume) and health care professionals (Ripich & Wykle 1996; Santo Pietro & Ostuni 2003). Language and

communication strategies may change based on a variety of factors such as the severity of impairment, stage of the disease, the nature and quality of relationship, and purpose of the interaction. However, the notion of personhood as an underlying philosophy for communicating with individuals with dementia is an approach that remains unchanged across these variations.

Despite impairment, with proper support, individuals with dementia are still able to engage in meaningful conversation (Sabat 2001; Tappen *et al.* 1997). Reliance on standardized testing techniques has resulted in a focus on the impairment of abilities, despite the reality that there are many retained communication, language and cognitive abilities (Hopper *et al.* 2001; Sabat & Collins 1999; Santo Pietro & Ostuni 2003) that can be capitalized upon during the initiation and maintenance of a conversation. Santo Pietro & Ostuni (2003) outline several abilities preserved into the later stages of Alzheimer's disease including the use of procedural memory, the ability to reach memories from earlier in life, to recite, read aloud and sing, engage in social ritual and the desire for interpersonal communication. In addition, Hopper and colleagues (2001) review cognitive-linguistic abilities that remain intact at various stages of the disease. For instance, moderate-stage individuals make meaningful statements in conversation, express needs, and reminisce about past events. The ability to receive and express nonverbal cues is preserved long after linguistic skills are severely diminished (Hoffman & Platt 1990). The following section will outline some of the ways in which communication and language can be adapted with a view to enhancing personhood while considering both the impaired and retained abilities of those with dementia.

Positive care interactions and communication strategies

Kitwood (1997a) contended that "positive person work", that which is accomplished through positive interactions, must occur continually in the care environment in order for individuals with dementia to receive high quality care. Representing a person-centered approach to care, positive interactions are those that involve nurturing, healing and ultimately meet psychological need. Kitwood described positive interactions as "warm" and "rich in feeling". The following five of Kitwood's positive interactions were chosen for examination here based on their applicability to communication and language considerations for individuals with dementia. They include: recognition, negotiation, validation, collaboration, and facilitation. These types of positive interactions are

discussed within the context of interactions between an individual with dementia and communicators who do not have dementia.

According to Kitwood (1997a), recognition occurs when an individual is known as a unique person by name, profiles or accomplishments. The individuality of a person is affirmed through recognition. Negotiation refers to instances when an individual is consulted about preferences, choices, and needs. Validation refers to the acceptance of reality, and acknowledging feelings of being alive, connected and real. The core features of validating are acknowledging the reality of the person's emotions and feelings, and responding to the validity of her/his feelings. Collaboration occurs when a caregiver aligns himself/herself with the person with dementia to engage in a task and to work together to achieve a common goal. Facilitation enables a person with dementia to do what he or she would otherwise be unable to do by furnishing missing parts of the intended action.

We were unable to make clear distinctions between the positive interaction categories of facilitation and collaboration in these "conversations for conversation's sake". Thus, we decided to collapse these categories and use the term facilitation, which is a major strategy used throughout the transcripts. This decision is supported by the analyses of Savundranayagam (2000), who also could not differentiate instances of facilitation and collaboration in published transcript illustrations of successful communication with individuals with dementia.

Recognition can be accomplished through the "simple act of greeting, or by careful listening over a long period of time" (Kitwood 1997a: 90). It involves both verbal and non-verbal aspects of communication (Kitwood 1997a). Recognition can involve asking an individual with dementia how he/she prefers to be addressed, and using this in subsequent communication encounters. Nonverbal behaviors such as direct eye contact and proximity considerations (e.g., getting down to her/his level if she/he is in a wheelchair) also are essential to successful recognition. To use the positive interaction feature of negotiation, it is necessary to ask questions of the individual with dementia. Researchers suggest that specific information, such as a preference, can be best ascertained using a close-ended or forced-choice format (Veall & Orange 2001). For instance, yes/no or multiple-choice types of questions provide options and are more easily understood due to retained abilities in recognition memory (Hopper 2001; Ripich et al. 1999). Obtaining correct information from the person with dementia can provide valuable insights about her/his preferences and needs, resulting in individualized care provision.

Validation requires the clear expression and understanding or acceptance of feelings and emotions. Savundranayagam (2000) noted that restatements, affirmations and matching comments/associations were the most frequent examples of validation used in conversations between health care professionals/researchers and individuals with dementia. Sabat (2001) reported that in his conversations with Dr. M (a client with dementia) he validated her feelings of inadequacy by restating her concerns about the difficulties associated with her dementia. This form of reflection framed within the intended emotional perspective made Dr. M feel more comfortable (i.e., interactive in a positive sense) in future communicative encounters.

The intent of facilitation [and collaboration] is to initiate, conduct and complete a task within the context of an interaction. Task initiation and completion can encompass the use of instructions (in the form of commands – direct or indirect) designed to enhance effective communication. With regard to a commonly voiced communication strategy for individuals with dementia, it is essential for caregivers to control the amount of information that their partners with dementia maintain in working memory (i.e., number of ideas or propositions), while simultaneously decreasing demands on long-term memory subsystems and processes (Bayles 2003; Rochon et al. 1994). Research suggests that instructions are better understood if they are short and limited to one- or two-step commands rather than as a lengthy series of instructions (Bayles 2003; Hopper 2001). This can be accomplished by breaking instructions into single steps and allowing the person with dementia to finish the first step of the task before instructing her/him to complete the next step. Camp (2003) suggests that care providers should always demonstrate first what is to be done by the individual with dementia prior to expecting a task to be executed.

Although several researchers suggest avoiding the use of open-ended questions with individuals with dementia (Ripich et al. 1999; Santo Pietro & Ostuni 2003; Veall & Orange 2001), there is evidence that open-ended questions can be useful in initiating a conversation. Tappen et al. (1997) examined conversations between nurses and individuals with advanced AD and determined that the use of broad openings (e.g., Tell me how you are feeling today) in the form of open-ended demands were successful in eliciting meaningful conversation. The authors stated that a simple opening statement often resulted in statements from the AD individual that revealed emotion and mood. The use of open-ended questions can also enable partners to initiate a desired or required task (e.g., spoken social interaction versus daily care routine). Initiating

a conversation also can be improved by choosing topics from autobiographical memory because it is a better preserved subcomponent of episodic memory that contains accessible, individualized, and personally relevant topics for those with AD (Santo Pietro & Ostuni 2003).

Conversations with individuals with dementia can be filled with silent gaps and semantically empty spoken language because of the common word-finding difficulties. Thus, the topic of conversation, or the point of utterances can be challenging to ascertain (Abbott & Orange 2001). Sabat suggests the use of a facilitative speech act termed indirect repair (Sabat 1991, 2001). According to Sabat (2001), "Indirect repair refers to inquiring about the intention of the speaker, through the use of questions marked not by interrogatives but by intonation patterns, to the use of rephrasing what you think the speaker said and checking to see if you understood his or her meaning correctly" (pp. 38–9). As well, Sabat (1991) suggests that partners should not interrupt the long pauses common in spoken output of individuals with AD because their thought may return slowly if they are not distracted by interruptions. Thus, facilitation can be achieved by allowing individuals with dementia more time to reflect and access thoughts before interrupting or offering potential words or propositions.

Conversational analysis for Kitwood's positive care interactions

From the Alzheimer's component of the Charlotte Narrative and Conversation Collection (2004; see introduction to this volume) with eight residents on a nursing home special care unit, we selected the 50 audio-recorded conversations held over a period of four years with Robbie Walters (pseudonym for an 80-year-old man in the moderate stage of dementia). It should be noted that most of the conversations were recorded in the first two years, after which Robbie Walters was reluctant to converse. These five–20-minute conversations with one or more regular conversational partners associated with the Project were transcribed, segmented into utterances and analyzed for examples of the Kitwood positive care interactions. Students enrolled in undergraduate courses in communication sciences and disorders were trained to transcribe, segment and code the discourse samples using the Codes for Human Analysis of Transcripts (CHAT) which is an internationally accepted discourse coding subsystem of the CHILDES program for analyses of discourse (MacWhinney 1995). An explanation of the meaning of the symbols in the examples is provided in the Appendix.

The context for these conversations was distinctive in that experienced communicators were interacting with Robbie Walters solely to generate conversation. The purpose of each encounter was to have a conversation, unlike in many long-term care situations where the object is to complete a specific care task. In this chapter, we aim to illustrate *conversation as care*. Conversation with an individual with dementia promotes personhood when the conversational partner shows continuing interest in the person and his/her life story, preferences, emotions and needs. The interrelated nature of the positive care interactions results in their overlap within conversation. For the present purposes, we include examples that show key features of Kitwood's positive care interactions of personhood.

Recognition

Initially, the project interviewers inquired how Robbie Walters would like to be addressed in conversation. His preference for being called Robbie was followed. In the first two conversational turns of Selection 1, the conversational partner's first three utterances recognize Robbie's uniqueness through a greeting, the use of his name, and an inquiry about how he was.

Table 2.1 Selection 1: Recognition, Negotiation, Creation

BD: Good morning Robbie.	RW: **Oh Well.**
BD: How are you sir?	BD: Okay?
RW: I'm fine.	RW: I can [# 4 seconds] uh # do any
BD: Gonna take a nap or talk to me or what?	of that almost any schedule.
	RW: It don't matter.
RW: I'm [/] I'm [/] I'm ready to do any of it I guess.	BD: Well the thing is # if you're ready for a good nap # I'd take it now.
BD: Well # what would you care to do?	
BD: It's your choice.	BD: [*laughs*]
RW: Uh # well # I probably would put takin(g) a nap at the top of the list.	RW: You mean things are gonna get rougher?
BD: Then you take a nap and next week I'll get here earlier # before you get sleepy.	BD: Naw I don't think they're [/] they're rough now are they?
	RW: No xxx.
RW: [*Chuckles*]	BD: No.

Negotiation

Many interactions with a person with dementia could potentially involve negotiation. The use of negotiation allows for a feeling of being in control, of being important, and of being valued. As demonstrated in Selection 1, negotiation may be as simple as asking Robbie if he wants to take a nap. This selection illustrates that BD enables Robbie to express and choose "taking a nap" over talking to her.

Selection 2, about how to address Robbie, is another example of negotiation. In this example, the conversation partner BD negotiates with Robbie about his preference concerning naming (recognition). With some effort, BD is able to learn that he does not want to be addressed as "Mister" but rather prefers to be called "Robbie."

Table 2.2 Selection 2: Negotiation

BD: Mister [//] what do [//] should we call [//] what should we call you?	RW: <no> [<overlap] not Mister.
	BD: All right.
	RW: Not used to that.
BD: How do you [+/.]	BD: [*chuckles*]
RW: I'm Robbie.	LM: So you like to be called
BD: Ahh.	Robbie.
RW: Robbie Wilson	RW: Well yes.
BD: Well Robbie it [//] is it [//] should I call you Mister Wilson or <Robbie> [overlap>]	LM: Okay.
	LM: We can do that.
	RW: Mhmm.

In Selection 3, the tape recorder was started in the middle of an ongoing topic. Robbie seems to be cold and under the impression that he has no sweater. Both conversation partners BD and LM continue to negotiate with Robbie to find a satisfactory solution. In the end, Robbie admits that "it is a little warmer out there."

Table 2.3 Selection 3: Negotiation

RW: ice have a chance to melt off of it	BD: What do you think?
BD: (*Laughed*)	LM: Or do you want to jus you know +...
LM: Ahhh	
BD: I know what you might do.	LM: It seems warmer out here than it did in that kitchen.
BO: What?	
BD: The +/.	RW: Well I believe it is a little warmer out here <than there> [overlap>].
RW: I [/] I [/] what ever [//] every [//] everybody all other human beings do all day.	LM: <Mmhm> [<overlap].
	LM: Uh huh
BD: Well this is true.	LM: You might want to sit up here then.
BD: I was gonna suggest a sweater.	
RW: Hmm?	BD: By the birds.
BD: Let's look in your room for a sweater.	LM: Where you were huh?
	RW: I don't care.
BD: It is chilly.	RW: Jus so it's warmer xxx.
RW: I don't have a sweater.	LM: Well let's see if it it's warmer up here.
BD: Shall we take a look an see if there's something else that we could borrow?	RW: Oh okay.
	BD: That sounds like a good plan.

Validation

In selections 4 and 5, the conversation partner (i.e., GN) responds to Robbie's feelings several times, first by validating his insecurity about task completion through encouragement. Secondly, feelings of loss experienced by Robbie about past activities are explored and acknowledged.

In Selection 4, GN validates Robbie's feelings of accomplishments in the German language. Although Robbie does not readily express his emotions, he feels pleased with the compliment. Robbie's pleasure clearly shows in his wish for GN to "Have a good week" and to "Take care."

Table 2.4 Selection 4: Validation, Giving

RW: I hope I can catch on.	GN: I'm very pleased.
GN: Yeah you [//] you're [/] you're very good.	RW: Have a good week.
GN: That's great.	GN: Yes same to you
GN: You're doing a fine job.	GN: Thanks very much.
RW: Thank you.	RW: Take care.

Selection 5 shows conversation partner GN persisting in trying to draw Robbie out about how he feels about his life. Validating Robbie's loss of being able to be "out-of-doors" results in Robbie producing an uncharacteristically long sentence: "Anything that # keeps me from enjoying the out-of-doors <well>."

Table 2.5 Selection 5: Validation, Giving

GN: You're [/] you're having a good time?	GN: Yeah.
	RW: Anything that # keeps me from enjoying the out-of-doors <well> [overlap>].
RW: Well I enjoy it yes.	
GN: That's fine.	CG: <Yeah> [<overlap].
RW: Yeah.	GN: Uh that's really what you are missing here, isn't it?
GN: Great.	
RW: Yeah # well <a little> [/] a little less exciting as [/] as you get older.	RW: mmh?
	GN: That's something that you're missing here.
GN: Yeah xx sometimes there could be a little bit more uh fun little more [/] # <more> [overlap>] activities.	RW: Yes.
	GN: When you sit in your chair and thinking about outdoor activities.
RW: <mmm> [<overlap].	
GN: Any activities that you miss particularly?	RW: Yeah.
	GN: Okay.
GN: Is it the fishing that you miss?	RW: Thanks for checking.
RW: Huh?	GN: Yeah.
GN: Do you miss the fishing most?	
RW: Uh # yeah I: [/] I like the out-of-doors.	

By definition, validation is the affirmation of feelings and emotions. Although the transcripts contained several examples of the other positive care personhood strategies, validation of particular emotions was non-existent. It is not possible to determine Robbie's premorbid emotionality. However, even though some of the topics discussed were potentially emotion evoking (e.g., family, growing up, etc.), Robbie did not often express emotion or feeling states in the course of the conversations.

Facilitation (and collaboration)

In Selection 6, conversation partner GN builds on Robbie's strengths and in the end GN enables Robbie to remember that he "liked all of them but I liked the raisin ones real well." This excerpt demonstrates how difficult it is for Robbie to remember what cookies he liked best and how, nevertheless, with the help of conversation partner GN Robbie is able to accomplish the task.

Table 2.6 Selection 6: Facilitation

GN: Did you also have <a nice> [//] uh some uh uh nice uh <cookies> [//] Christmas uh cookies?	RW: Well.
RW: Yeah mother usually always baked the cookies.	GN: Like butter cookies?
GN: I see.	GN: Or # butter made cookies?
GN: Which one did you like best?	GN: Or was it uh more with uh nuts?
RW: Uh.	GN: The ones with nuts?
GN: Er were there any that you uh liked in particular?	GN: Or with raisins?
	GN: Or did you like all of them?
	RW: I liked all of them but I liked the raisin ones real well.

In addition, Selection 7 illustrates how the use of facilitation enables Robbie to provide specific information about a much-enjoyed activity. For example "he had a bird dog" enables Robbie to provide the specific name "Shelley Berdette" and the fluent sentence: "Bird dogs were expensive things back then." In this excerpt, shared interest about hunting gives conversation partner BD the opportunity to provide Robbie with the missing parts of the conversation. As evidenced in this selection, shared background knowledge can be a special resource (Tappen *et al.* 1997).

Table 2.7 Selection 7: Facilitation

BD: What else did you play besides baseball?	RW: Yeah.
RW: Hmm?	BD: He had a bird dog
BD: Did you play anything else besides baseball?	RW: Yeah well # uh there's uh with us xxx available Shelley Berdette.
RW: Oh a little bit of [//] all of it you know.	RW: He uh # had a bird dog.
RW: Umm played a little bit of basketball.	RW: Bird dogs were expensive things back then.
RW: And uh [# *4 seconds*] we did a lot of # hunting and things like that on the hills	BD: Yeah.
	BD: Yep.
RW: an uh xxx +...	BD: What kind did he have?
BD: That's pleasant.	BD: Do you remember?
RW: mhmm.	RW: Ah he had a pointer.
BD: What did you hunt rabbits squirrel?	BD: Oh they were the good ones. [# *7 seconds*]
RW: Squirrel and a +...	BD: Now quail [//] huntin' quail is not easy.
RW: Yeah <in the summers> [//] an in the summertime or in the other season it [/] it would be an [/] an +...	RW: Well if you have a good quail dog of course you can <get your> [//] get [//] gain an advantage (on) their position an and uh +...
RW: Ah we'd hunt # uh the other animals.	
RW: Whatever was in season.	RW: We hunted down through the plant areas you know back then near Viscos an on Santos an wherever good territory.
BD: Did you ever hunt quail?	
RW: Oh yes.	
RW: That was *my favorite*.	
BD: That's what my uncle hunted.	

Role of the individual with dementia in promoting personhood

The personhood strategies discussed thus far have concentrated on the caregiver or conversation partner as the facilitator for the individual with dementia. However, Kitwood (1997a) suggests there are instances when the individual with dementia contributes to an interaction in a more primary fashion. In this situation, the individual with dementia takes the lead and the caregiver affirms the interaction. Kitwood (1997a) identifies *creation* and *giving* as two common examples of this sort of interaction. Creation occurs when the individual with dementia "offers something to the social setting, from his or her stock of ability and social

skill" (p. 92) while giving is the act of expressing concern or affection, or making an offer of help (Kitwood 1997a).

These two concepts have not been previously explored from a purely communicative perspective, but Kitwood and Bredin (1992) identify "indicators of relative well-being," that is, abilities that can be shared by the healthy and those with dementia and include, among others, the ability to initiate social contact, humor, and show pleasure. Sabat (2001) provided empirical evidence of indicators of relative well-being by exploring the case of an individual with Alzheimer's disease (AD), Mrs. F. He demonstrated that even though she was experiencing decline in a number of cognitive areas, she still evidenced numerous indicators of relative well-being such as expressing a wide range of emotions, asserting desire or will, and the ability to be humorous. He pointed out that if one were to base interactions with Mrs. F. on the decline associated with AD then one would not recognize the abilities and attributes that have remained intact despite the disease.

Selections 8 and 9 are examples of Kitwood's concept of creation whereby Robbie spontaneously provides content to the conversation based on his humorous statements. In both of these examples, he offers "one-liners" that are extremely witty (Selection 8, "Wasn't intended for the rest of the day was it?" and Selection 9, "Oh I thought maybe I slept in the woods. I'm sure glad it wasn't that"; "You don't know who your neighbors are."). As well, in Selection 1, Robbie responds to conversation partner BD's advice to take a nap now if he is ready by stating: "You mean things are gonna get rougher?", again demonstrating his ability to offer humor to his conversational partner.

Sharing humor in conversation involves bonding and emotional closeness and, in these examples, provides an opportunity for Robbie to affirm his personhood through his ability to make people laugh.

Table 2.8   Selection 8: Creation

LM: What do you like?	BD: I'll eat it for breakfast but not
RW: Well I like bacon.	for the rest of the day
RW: I like about any breakfast.	LM: Mmm.
RW: I'm a breakfast man.	RW: Wasn't intended for the rest of
LM: You're a breakfast man?	the day was it?
BD: I am too.	LM: [*Laughs*]
BD: I don't care what it is.	BD: [*Laughs*]
	RW: Ahhh.

Table 2.9   Selection 9: Creation

LM: We saw you nappin a minute ago.	LM: [*Laughs*]
RW: Where about?	BD: I would much rather go to sleep in the woods quite frankly.
LM: Right here.	RW: Huh?
LM: You were asleep when we come in the room.	BD: It'd be more fun in the woods.
RW: Oh I thought maybe I fell asleep in the woods.	RW: You don't know who your neighbors are.
RW: I'm sure glad it wasn't that.	BD: Well that's true.
	BD: That is true.

In Selection 10 Robbie and his conversation partner GN are working on a few activities together involving counting and identifying pictures on cards. It begins with GN validating Robbie's attempts to answer questions about the activity and ends with a demonstration of Kitwood's notion of giving. That is, Robbie states his gratitude to GN, demonstrating a clear ability to express his appreciation. Also, in Selection 5, Robbie says "Thanks for checking" after GN validates Robbie's missing the outdoors/longing for a past activity. Both selections exemplify the ability of the individual with dementia to "give" in the conversational encounter.

Table 2.10   Selection 10: Giving

GN: Right.	GN: Yeah.
GN: Good.	GN: I like it [//] <I like coming> [overlap>].
GN: I like it.	
GN: Very good!	RW: <and giving> [<overlap] giving some of your time.
GN: You remember a lot!	
RW: I appreciate it [//] your stopping by.	GN: Yeah.

Humor and the expression of gratitude are only two possible mechanisms through which individuals with dementia can contribute meaningfully to conversations, making explicit affirmations of their own personhood in the process. Analyzing the conversational excerpts presented herein leaves one with the strong impression that Robbie, as a person living with dementia, is still capable of communicating his desires and feelings, and equally important, is able to experience some form of personal growth, even in the face of cognitive decline.

Conclusions and implications

The interaction between staff and residents with dementia in long-term care has been demonstrated to be minimal (Hallberg *et al.* 1990; Ward *et al.* 1992) with various reasons cited for limited interaction. Kitwood (1997a) recognizes the time constraints that exist for staff in long-term care facilities and suggests that interactions do not necessarily need to be of longer duration, rather each interaction needs to be of higher quality. The positive care interactions discussed in this chapter have the potential to improve interactions in long-term care facilities by the implementation of a communicative approach based on enhancing personhood. Although task completion was not the focus of the conversations analyzed, the personhood communication strategies could be used as a means of facilitating meaningful conversation during the completion of essential tasks (e.g., personal care) (Souren & Franssen 1993).

The failure to communicate with individuals with dementia in a fashion congruent with a personhood perspective may result in episodes of care characterized by Kitwood as malignant social psychology. Kitwood identifies 17 elements (e.g., withholding, ignoring, invalidation) that contribute to a malignant social psychology based on episodes of care involving individuals with dementia that he witnessed and subsequently classified. He points out that malignant does not refer to intent by caregivers, rather is a component of our "cultural inheritance". Many, if not all of these elements are affected by various components of communication and some could arguably be considered polar opposites of the positive care interactions discussed thus far. For example, imposition is identified as "forcing a person to do something, overriding desire or denying the possibility of choice on their part" (1997a: 47). Failing to use negotiation as a strategy for communication could result in imposition, as defined by Kitwood. Also, disempowerment, that is, not allowing a person to use the abilities that they do have; failing to help [an individual with dementia] complete actions that they have initiated" (p. 46), could arise if retained communication abilities are not considered and/ or facilitation is not utilized during care interactions.

Discourse analyses for individuals with dementia can be used for the purposes of differential diagnosis, identifying linguistic and interactional strengths and weakness of conversational participants, monitoring disease progression, and developing or affirming theoretical frameworks of interaction, among others (Duong *et al.* 2003; Orange & Kertesz 2000). In this chapter, the discourse analyses revealed competencies of Robbie that to casual observers or conversational partners may not have been entirely obvious or viewed as a strength upon which to build collaborative,

caring and rewardingly positive interactions. For example, long pauses (i.e., >5 seconds) provided by the conversational partners gave Robbie time to formulate independently his utterances and responses to questions. Moreover, the use of proper nouns rather than pronouns by the conversational partners facilitated the forward progression of "problem-free" conversation, giving Robbie the names of objects and people that helped circumvent his anomia.

While specific communication and language-based strategies for individuals with dementia have been described in the literature, one could employ personhood as an underlying philosophy in communication education and training programs for formal care providers. Indeed, we now see that the goal of affirming personhood underlies the entire positive feedback loop characterized by our Communication Enhancement Model as it applies to dyadic communication of a health provider and an older adult, with intact cognition or with impaired cognition (Orange *et al.* 1995; Ryan *et al.* 1995). In terms of educating and training, interactions that affirm personhood should be the gold standard, whether one is communicating for purposes of social interaction or to complete agenda-driven tasks. Caring for a person with dementia based on a social interactive framework that incorporates positive care personhood-affirming strategies is likely to be more rewarding than completing repetitive, task-oriented activities that only serve to shape dependence. Caregivers affirming the personhood of vulnerable individuals whose sense of self unfolds within their conversational interactions can also then participate, at least occasionally, in the warmth of reciprocity.

Appendix

Key for codes used to represent conversational features (MacWhinney, 1995)

#	= pauses of less than 2 seconds
[/]	= repetition
[//]	= retracings with corrections
<>	= marks boundaries of the targeted feature
[overlap]	= marks simultaneous talk
xx	= unclear, untranscribable word
xxx	= unclear, untranscribable words
( )	= material inside parentheses are omitted by speaker but included in transcript to add clarity
"	= tag question
+...	= trailing off; incomplete utterance
+/.	= interruption; when one speaker is interrupted by another speaker

Acknowledgments

References

Abbott, B. & Orange, J.B. (2001, July) "Communication breakdown, topic management, and dementia of the Alzheimer's type". Paper presented at the 17th World Congress of the International Association of Gerontology. *Gerontology: International Journal of Experimental, Clinical, and Behavioural Gerontology*, 47(S1): 90.

Bayles, K.A., (2003) "Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients". *Journal of Communication Disorders*, 36(3): 209–19.

Bayles, K.A., Tomoeda, C.K., Cruz, R.F., & Mahendra, N. (2000) "Communication abilities of individuals with late-stage Alzheimer disease". *Alzheimer Disease and Associated Disorders*, 14(3): 176–81.

Camp, C. (2003, June) "Montessori and spaced retrieval: effective interventions for the cognitively impaired." 20th Annual Summer Institute on Gerontology, McMaster University, Hamilton, Canada.

Causino Lamar, M.A., Obler, L.K., Knoefel, J.E., & Martin, A.L. (1994) "Communication Patterns in End-Stage Alzheimer's Disease: Pragmatic Analyses", in Bloom, R.L., Obler, L.K., De Santi, S., & Ehrlich, J.S. (eds.). *Discourse Analysis and Application: Studies in Adult Clinical Populations* (pp. 217–35) Hillsdale, NJ: Lawrence Erlbaum Associates.

Charlotte Narrative and Conversation Collection (2004). *New South Voices home page*. Retrieved September 3, 2004 from http://newsouthvoices.uncc.edu/trial.jsp.edu/cncc.jsp.

Duong, A., Tardiff, A., & Ska, B. (2003) "Discourse about discourse: what is it and how does it progress in Alzheimer's disease?". *Brain and Cognition*, 53(2): 177–80.

Hallberg, I.R., Norberg, A., & Eriksson, S. (1990) "A comparison between the care of vocally disruptive patients and that of other residents at psychogeriatric wards". *Journal of Advanced Nursing* 15: 410–16.

Hallberg, I.R., Norberg, A., & Johnsson, K. (1993) "Verbal interaction during the lunch-meal between caregivers and vocally disruptive demented patients". *The American Journal of Alzheimer's Care and Related Disorders and Research* 8(3): 26–32.

Harris, P.B. (ed.) (2002) *The Person with Alzheimer's Disease: Pathways to Understanding the Experience*. Baltimore: Johns Hopkins University Press.

Hoffman, S.B., & Platt, C.A. (1990) *Comforting the Confused: Strategies for Managing Dementia*. NY: Springer.

Hopper, T. (2001) "Indirect interventions to facilitate communication in Alzheimer's disease". *Seminars in Speech and Language* 22(4): 305–18.

Hopper, T., Bayles, K.A., & Kim, E. (2001) "Retained neuropsychological abilities of individuals with Alzheimer's disease". *Seminars in Speech and Language* 22: 261–73.

Kempler, D. (1995) "Language Changes in Dementia of the Alzheimer Type". In R. Lubinski (ed.) *Dementia and Communication* (pp. 98–114). Philadelphia: B.C. Decker Publishing.

Kitwood, T. (1997a) *Dementia Reconsidered: The Person Comes First*. Philadelphia: Open University Press.

Kitwood, T. (1997b) "The Experience of Dementia". *Aging and Mental Health*, 1(1): 13–22.

Kitwood, T. (1998) "Towards a theory of dementia care: Ethics and interaction". *The Journal of Clinical Ethics* 9(1): 23–34.

Kitwood, T. & Bredin, K. (1992) "Towards a theory of dementia care: personhood and well-being". *Ageing and Society*, 12: 269–87.

Luborsky, M. (1994) "The cultural adversity of physical disability: erosion of full adult personhood". *Journal Of Aging Studies* 8: 239–53.

McWhinney, B. (1995) *The CHILDES Project: Tools for Analyzing Talk*. 2nd edition. Hillsdale, NJ: Lawrence Erlbaum Associates.

Orange, J.B. & Kertesz, A. (2000) "Discourse analyses and dementia." *Brain and Language*, 71: 172–4.

Orange, J.B., Ryan, E.B., Meredith, S.D., & MacLean, M.J. (1995) "Application of the communication enhancement model for longterm care residents with Alzheimer's disease." *Topics in Language Disorders*, 15(2): 20–35.

Post, S.G. (2000) *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying*. Baltimore: Johns Hopkins University Press.

Ripich, D.N. & Wykle, M.L. (1996) *Alzheimer's Disease Communication Guide: The FOCUSED Program for Caregivers*. San Antonio, TX: The Psychological Corporation.

Ripich, D.N. & Ziol, E. (1998) "Dementia: A Review for the Speech-Language Pathologist", in A.F. Johnson & B.H. Jacobson (eds.) *Medical Speech-Language Pathology: A Practitioner's Guide* (pp. 467–94). NY: Thieme.

Ripich, D.N., Ziol, E., Fritsch, T., & Durand, E.J. (1999) "Training Alzheimer's disease caregivers for successful communication". *Clinical Gerontologist*, 21(1): 37–56.

Rochon, E., Waters, G.S., & Caplan, D. (1994) "Sentence comprehension in patients with Alzheimer's disease". *Brain and Language*, 46: 329–49.

Ronch, J.L. & Goldfield, J. (eds.) (2003) *Mental Wellness in Aging: Strengths-Based Approaches*. Baltimore: Health Professions Press.

Ryan, E.B., Meredith, S.D., MacLean, M.J., & Orange, J.B. (1995) "Changing the way we talk with elders: promoting health using the communication enhancement model." *International Journal of Aging and Human Development*, 41: 89–107.

Sabat, S.R. (1991) "Turn-taking, turn-giving, and Alzheimer's disease: a case study of conversation". *The Georgetown Journal of Languages and Linguistics* 2: 284–96.

Sabat, S.R. (2001) *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Massachusetts: Blackwell.

Sabat, S.R. & Collins, M. (1999) "Intact, social, cognitive ability, and selfhood: a case study of Alzheimer's disease". *American Journal of Alzheimer's Disease*, January/February.

Santo Pietro, M.J. & Ostuni, E. (2003) *Successful Communication with Persons with Alzheimer's Disease – An In-Service Manual.* 2nd Edition. St. Louis, Mo.: Butterworth-Heinemann.

Savundránayagam, M.Y. (2000) "Personhood and effective communication with persons with dementia." Paper presented at the annual meeting of the Gerontological Society, Washington, D.C.

Souren, L. & Franssen, E. (1993) *Broken Connections: Alzheimer's Disease, Part II – Practical Guidelines for Caring for the Alzheimer Patient.* Berwyn, PA: Swets and Zeitlinger.

Tappen, R.M., Williams-Burgess, C., Edelstein, J., Touhy, T., & Fishman, S. (1997) "Communicating with individuals with Alzheimer's disease: Examination of recommended strategies". *Archives of Psychiatric Nursing* 21: 249–56.

Veall, J. & Orange, J.B. (2001, July) "Question comprehension by individuals with dementia of the Alzheimer's type." Paper presented at the 17th World Congress of the International Association of Gerontology. *Gerontology: International Journal of Experimental, Clinical, and Behavioural Gerontology*, 47(S1): 91.

Ward, T., Murphy, B., Procter, A., & Weinman, J. (1992) "An observational study of two long-stay psychogeriatric wards". *International Journal of Geriatric Psychiatry*, 7: 211–17.