

Finding a New Voice

Writing Through Health Adversity

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This memorial tribute to James J. Bradac draws on lessons friends and colleagues learned through his witness of living well with serious disability. Analysis of published disability narratives provides the basis for identifying how writing for self and others empowers persons with acquired disability. Acquiring a disability can threaten a person's sense of self and ability to communicate effectively with others. Journal writing allows individuals to rediscover their sense of self, to release complex emotions by naming them, and work their way through the many changes in their daily lives. In particular, a person acquiring a disability must learn how to balance efforts to maintain "normality" with the need to accept changes. Writing for others helps the author clarify personal experience, find meaning, and make a valuable social contribution. Specific benefits of the written social voice are outlined in terms of both process and outcomes. Published illness narratives put a face on disability, engender empathy, advocate for a "disability-friendly" society, and show how the human spirit can transcend disability.

Keywords: *disability, written communication, narratives, empowerment, communication predicaments, selective assertiveness, Alzheimer's Disease*

Bore the moment to the core.
Drain duration from the day.
Once, this I could have done
when I saw the morning sun
refracting
upon apricots
in a crystal bowl.

—J. J. Bradac (1995, p. 27)

Jim Bradac lost his ability to move and to speak because of Amyotrophic Lateral Sclerosis (ALS). However, he lost neither his personal voice nor his academic voice

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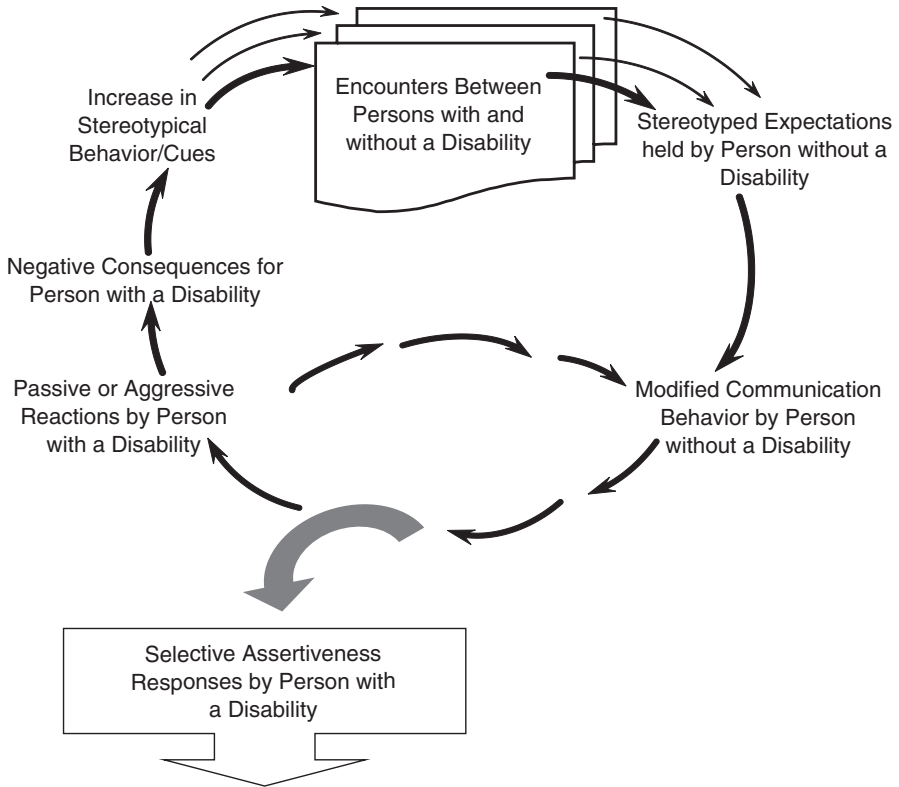
as a communication scholar over those years of paralysis. Through personal motivation, commitment, social support, and new technologies, he was able to use the power of writing to maintain communication and to increase his legacy through academic works, journal editing, mentoring, and poetry. For this article, published disability memoirs were analyzed to demonstrate how persons with acquired disability or serious chronic illness use writing to serve personal and social identity goals.

Impact of Disability on One's Voice

As Arthur Frank (1991, 1995) has cogently argued, acquired disability or serious illness threatens one's sense of identity and, relatedly, both one's inner voice and one's social voice. Changes in physical, sensory, and/or cognitive abilities, and current and future changes in the ability to manage basic daily activities, challenge personal identity. Adaptations in social identity are required because both visible and invisible changes affect social interactions and enactment of social roles. In terms of key concepts in the field of language and social psychology, acquired disability alters our senses of personal and social identities, how others perceive and communicate with us, and how we perceive and communicate with others (see Braithwaite & Thompson, 2000; Fox & Giles, 1997). Our personal story no longer seems to fit, and it can be a long, hard road to reconstruct our sense of self and their accompanying story.

For the intergroup communication text recently edited by Harwood and Giles (2005), my colleagues and I adapted an earlier model of communication and aging for a model of the Communication Predicament of Disability (Ryan, Bajorek, Beaman, & Anas, 2005; Ryan, Giles, Bartolucci, & Henwood, 1986; see Figure 1). Encounters with nondisabled persons can create communication predicaments for persons with a disability especially when able-bodied persons modify their communication in line with negative stereotypes of disability (e.g., unattractive, incompetent, slow, ill, cranky, unproductive). Such constraining communication can include overhelping, dismissiveness, shouting, high pitch, exaggerated intonation, avoidance, staring, and intrusive questions. As well, conversational partners may focus on disabilities or address third persons about the needs or wishes of individuals with a disability as though they are not present. In Jim Bradac's terminology, acquiring disability reduces one's power in conversation and creates uncomfortable situations because of uncertainty on the part of individuals with a disability and their conversational partners (Bradac, 2001; Ng & Bradac, 1993). Key communication predicaments for individuals with a disability include managing help (including overhelping and inappropriate help) and managing disclosure (Braithwaite & Thompson, 2000; Gallois, 2004; Ryan et al., 2005). Particularly in the early stages, the threatened voices

Figure 1
The Communication Predicament of Disability:
Interrupting the Cycle With Selective Assertiveness



Source: Ryan et al. in Harwood and Giles (2005, p. 120). Reprinted with permission from the publisher.

and weakened identities of persons with disability can lead them to be more reliant on the behavior of others as a social mirror, powerless as others shape their new identities.

Frank (1995) demonstrated through his own tale of the wounded storyteller and a sociological analysis of illness narratives that persons with a disability or chronic illnesses need to become storytellers to recover the voices that illness and its treatment have taken away. My focus in this article is on how writing for oneself and for others can assist individuals in finding their stories and sharing them.

Table 1
Reasons for Writing Disability Narratives

Inner Voice	Social Voice
Find positive meaning	Put a face on disability
Emotional outlet	Recover a sense of belonging
Convert emotion and images to words and story	Connect with a new ingroup
Adjustment in goals and activities	Help others with same disability
See self in wider context	Achieve sense of accomplishment
Learn lessons	Share emerging identity
Express creativity	Create empathy
Find humor	Educate (especially health providers)
	Advocate for social change

Finding the Inner Voice Through Writing

As Booth (1992) stated, writing well about losses transforms them: “a triumph of imagination” (p. 94). Table 1 presents key components in the process of reconstructing one’s personal and social identities through writing.

Faced with a damaged body, a person is forced to consider mortality. As well, the fact that one has survived the acquisition of bodily impairments helps shape a new identity, which can be resilient to further losses. The process can involve learning that the new self has the disability or progressive illness inextricably associated with it.

The poet Coleridge observed that it is the convalescent who sees the world in its true colors, and, as a convalescent, I have been forced into a renewed acquaintanceship with my body and into the painful realization that I am, like it or not, imprisoned in it. (McCrum, 1998, p. 3)

I feel so deprived of my self being unable to write, cut off since early January from all that I mean about my life, that I think I must try to write a few lines every day. It is a way of being self-supporting. (Sarton, 1989, p. 1)

Feeling thus deprived of a legitimate self, I can try to imagine an MS-less Nancy. And since writing has always formed the core of my identity, the means whereby I have saved and shaped my life, I wonder in particular whether I’d have become a writer if I hadn’t developed this disease. In all likelihood, I would. From the age of thirteen I claimed writing to be my “future profession.” But I could not conceivably have become the writer I am. Just as demyelinated lesions have spread throughout my central nervous system, their consequences have pervaded every region of my existence. (Mairs, 1986, pp. 17-18)

Regardless of objective difficulties, our responses to life lead to the creation of meaning (Frankl, 1963). Writing in a journal assists in the process of finding meaning as one gains perspective, recognizes choices, and reflects on them. Writing can

also take a person beyond the endless loop thinking in the “why me?” stage, when ominous or problematic possibilities spin around our vulnerable mind. Writing also helps a person threatened by depression see through the distortions of catastrophic thinking (i.e., believing that woes are more permanent, generalized, and caused by the self than they are in reality).

This work was my way of attempting to come to an understanding of my own blindness. (Michalko, 1998, p. ix)

Writing the book has been a way to make sense of an extraordinary personal upheaval, whose consequences will be with me until I die. (Mccrum, 1998, p. 2)

Pennebaker’s decades of research on repeated writing about traumatic events has shown that emotional writing is highly beneficial (Smyth & Pennebaker, 1999). He and his colleagues have argued that the integration of thoughts and feelings enables the construction of a coherent story about an experience. The act of transforming emotions and images into words can subsequently alter the way in which traumatic memories are organized, contemplated, and even forgotten. Translating emotions into words and personal narrative through writing often results in improvements in mental and physical health indicators, even when there is no external audience as in writing in a diary (Pennebaker & Seagal, 1999; Smyth & Pennebaker, 1999).

Many autobiographical writers began with a journal and make eloquent use of journal entries in their publications to express the feelings and understandings they were experiencing during particular episodes (Becker, 2004; Klein, 1997; Sacks, 1984).

The experience of living with cancer was so monumental that I regularly found myself at my computer writing about it. Initially, I wrote for my own self and my own therapy. (Poulson, 2002, pp. 190-191)

I began to keep a diary. This was Sarah’s idea, and I later discovered that she was writing one, too. I think the diaries helped preserve sanity for both of us. . . . I found myself expressing my feelings quite freely. (Mccrum, 1998, p. 55)

Through regular writing about one’s experiences, one finds words for emotions and images. Naming an experience through words, finding metaphor to capture its personal meaning, can be very powerful (Smyth & Pennebaker, 1999). The following quotations include vivid metaphors describing the world of a person with disability:

The brain of the race is so permeated with color that it dyes even the speech of the blind. Every object I think of is stained with the hue that belongs to it by association and memory. (Keller, 1908/2003, p. 78)

In the end, this book is about becoming silent, while all around cars honk impatiently. (DeBaggio, 2003, p. 5)

As one who has suffered from the malady in extremis yet returned to tell the tale, I would lobby for a truly arresting designation. “Brainstorm,” for instance, has unfortunately been preempted. (Styron, 1982, p. 58)

The scooter . . . was sportif. My self-image changed. I sat straight and high. (Klein, 1997, p. 345)

According to Goldberg (2000), we need to “write and write” for ourselves before we each find our story to write for others. The process of finding our stories often involves restorying, reframing the events in a more productive way within a broader context (Kenyon & Randall, 1997). One might, as in the Styron (1982) quotation above, move from a chaos script to the quest script, paralleling the hero’s journey in mythology through the call, initiation, and return with lessons learned (Campbell, 2001; Frank, 1995).

Writing can also be helpful in the inevitable adjustments of goals and activities associated with disability or chronic illness. These quotations highlight the role of a clear statement of dilemma and of identifying a powerful metaphor to carry one forward in a new direction:

I keep wondering if true acceptance means to stop challenging myself to do things as I used to, which was exhausting even when I was “normal,” and avoid the frustrating comparison with Before. (Klein, 1997, p. 316)

We are adjusting our dance steps to the changing melody of dementia, listening to the music within, as well as being encouraged by the supportive music around us. (Bryden, 2005, p. 13)

A common theme in recovering identity is the perception of benefits, such as strengthened relationships, positive personality change, and valued changes in priorities (Kubler-Ross & Kessler, 2000; Tennen & Affleck, 1999). Specifying lessons learned is a particularly therapeutic activity.

Illness is something to recover from if you can, but recovery is worth only as much as what you learn about the life you are regaining. (Frank, 1991, p. 2)

“I am sorry it happened to you,” wrote Luria [in a personal letter], “but if such a thing happens it can only be understood, and used. Perhaps it was your destiny to have the experience; certainly it is your duty now to understand and explore. . . . Really you are opening and discovering a new field.” (Sacks, 1984, p. 197)

Alzheimer’s provided me an opportunity to give up dirt and search the rocky hillsides of memory for places where freshets remained to tell me who I was and where I have been. (DeBaggio, 2003, p. 74)

I’ve learned that the incidents associated with aging—including this stroke—can be used for our spiritual healing, provided we learn to see through new eyes. (Dass, 2000, p. 6)

Rediscovery was the best part of my recovery—the way it made things new again. If I was careful, I could sometimes keep the window of newness open, keep the familiarity from rushing back in. (Becker, 2004, p. 228)

My patients knew that I understood what I was saying when I told them that they would have to modify their lifestyle and activities. They knew I understood it when I told them that it was difficult. And yet, I was living proof of the power of the human spirit to adapt to great adversity and carry on with a productive and rewarding life. (Poulson, 2002, p. 116)

Through his illness memoir, Norman Cousins (1979) virtually opened the eyes of the public and medical community to the potential healing benefits of laughter. Humor is also an important part of gaining perspective on one's own problems and seeing them as part of the human condition.

Knowing that I was always looking for the funny side of any situation and that I could laugh at myself readily made people less anxious about how they should interact in order to be helpful. (Poulson, 2002, p. 83)

Personal writing can be a very important way for ill people to identify new ways to express and enjoy their creativity.

Writer is not a bad thing to be if you're blind. (Kleege, 1999, p. 17)

I have started to write poetry. . . . This is very expressive and so much fun. I make up poems as I feel moved, and I am collecting them in a personal book that I will someday share with my children. (Truscott, 2004, p. 96)

Tanya enjoyed my blindness. Enjoyment was a reaction to blindness which I had never experienced before. This made me consider the possibility of enjoying blindness and thus enjoying life as a blind person. (Michalko, 1998, p. ii)

Finding and Expressing the Social Voice Through Writing

As outlined in column 2 of Table 1, writing for publication about one's disability or illness experience accomplishes a number of important goals, serving one's personal and social identities. These writings put a face on disability.

The leg had vanished, taking its "place" with it. Thus there seemed no possibility of recovering it. . . . I could no longer remember having a leg. I could no longer remember how I had ever walked and climbed. . . . There was a gap—an absolute gap—between then and now; and in that gap, into the void, the former "I" had vanished. (Sacks, 1984, pp. 85-86)

SBK: I remember the letter board getting lost, over and over again. Why the hell didn't they have an extra one?

Skip Peerless (physician): The letter board is considered a minor item overall.

SBK: It was my life line. (Klein, 1997, pp. 138-139)

"Down here!" I kept whimpering at the hips and buttocks and bellies pressing my wheelchair on all sides. "Down here! There's a person down here!" My only recourse was to roll to one side and hug a wall. (Mairs, 1986, p. 71)

With failing memory, it is difficult to write long passages without getting lost in words. Where does the story go? (DeBaggio, 2002, p. 57)

Disability writers recover a sense of belonging as they reach out to a new ingroup: others with similar disabilities or with similar disability experiences. Their senses of productivity return as they validate emotions and share solutions to everyday problems. They can share their sense of emerging identity and in the process further sharpen it.

I would love to see some people with Alzheimer's not trying to stay in the shadows all the time but to say, damn it, we're people too. And we want to be talked to and respected as if we were honest to God real people. (Henderson & Andrews, 1998, p. 7)

I have written this book to help those who have suffered as I did, and indeed for anyone recovering from what doctors call "an insult to the brain." I've also written it for families and loved ones who, sucked into the vortex of catastrophic illness, find themselves searching for words of encouragement and explanation. (McCrum, 1998, p. 1)

The book's ending, which had eluded me, is now finally clear. The stroke has given me a new perspective to share about aging, a perspective that says, "Don't be a wise elder, be an incarnation of wisdom." (Dass, 2000, p. 7)

I have spent most of my life living with the idea that I am a person first and blind second. These people have taught me that my blindness is part of who I am and that I am not a person who "happens to be blind" but, instead, that I am a "blind person." They have taught me that blindness has influenced my life and that I would be a different person were I not blind. (Michalko, 1998, p. iv)

Writing this book made me blind. . . . Today I am likely to identify myself as blind; five or six years ago I would have been more likely to use less precise phrases, such as "visually impaired" or "partially sighted." Since I began this book I have learned to use braille and started to carry a white cane. (Kleege, 1999, p. 1)

We all have a self-protective tendency to feel invulnerable despite what we know deep down about the human condition. Thus, it is immensely helpful to hear life stories of people who are vulnerable, can admit to it, and survive. We are open to learning, particularly from the authority of stories concerning changes in perspective about disability—not from being a superior person but from having returned from a quest journey with lessons learned (Campbell, 2001; Frank, 1993).

This book is more of my “advance scout” role. These days I’m the advance scout for the experiences of aging, and I’ve come back from the scouting party to bring good news. (Dass, 2000, p. 204)

This memory of my relative indifference is important because such indifference demonstrates powerfully the outsider’s inability to grasp the essence of the illness. (Styron, 1982, p. 38)

More like a Baedeker for a country to which no one travels willingly: the observations and responses of a single wayfarer who hopes, in sketching her own experiences, to make the terrain seem less alien, less perilous, and far more amusing than the myths and legends about it would suggest. (Mairs, 1986, p. 14)

To all concerned, this book is meant to send a ghostly signal across the dark universe of ill-health that says, “You are not alone.” (McCrum, 1998, p. 2)

Central to the social voice in disability narratives is the desire to educate others and to advocate for social change (i.e., increased awareness of the societal responsibility for the extent of disability individuals with various bodily impairments experience). Kleinman (1988) has argued that medical providers and other caregivers need to hear individual illness narratives because periods of alleviation and exacerbation in the course of living with disability or chronic illness are often driven more by psychological or social experiences than by biology.

When I was given a diagnosis of aggressive inflammatory carcinoma, I found myself transformed from one who orders and administers medication to a terrified recipient. Until then, I had felt that I was a particularly empathetic doctor who listened to and, I thought, heard the stories of my patients. It was a shock, then, to undergo the foreign and surreal experience of becoming a patient. (Poulson, 2002, p. 209)

The resistance that I and other incompletely blind people encounter in our desire to learn braille has finally to do with issues of identity. If the ability to read print is what distinguishes the sighted from the blind, the way we read defines who we are. In wishing to learn braille I seemed to be abdicating my identity as a sighted person with a visual impairment and taking on a new identity as a blind person who rejects the sight she has. (Kleege, 1999, p. 217)

Treatment strategies should aim to empower us, encourage the creation of relationships, and restore the capacity for trust, autonomy, initiative, competence, identity and intimacy. (Bryden, 2005, p. 134)

Maybe “independence” is a misleading concept. Each of us is dependent on others. Perhaps independence is not the ultimate goal, but interdependence: the possibility of doing with and for each other, the ability to ask for the help that we each need. (Klein, 1997, p. 316)

There are rewards for making the world physically and emotionally accessible to all people, including benefits that accrue to society as a whole. The more perspectives that

can be brought to bear on human experience, even from the slant of a wheelchair or a hospital bed, or through the ears of a blind person or the fingers of someone who is deaf, the richer that experience becomes. If it is both possible and pleasant for me and my kind to enter, the world will become a livelier place. You'll see. (Mairs, 1986, p. 121)

Specific Benefits of the Written Social Voice

My life is certainly unusual now: no real speech, no breathing, no eating, and no running toward the sky, orange trees, dogs and kids. But I can still think, for good or for ill, and I can communicate the results of this thinking, thanks to some astounding computer magic. (Bradac, 1998, pp. 4-5)

For Jim Bradac and others whose voices have otherwise been silenced, written messages and documents return to them the world of verbal communication. The message, unlike speech, is separate from the real-time process of its creation. Control over timing and topic and the invisibility of personal and technological assistance normalizes communication. Writing poetry, in particular, offers a creative opportunity to communicate metaphor, images, and feelings without being tied to the usual expectations for word accuracy, grammar, and coherence of ideas.

I would, for instance, find no impediment to committing my thoughts to paper—but then have the greatest difficulty in expressing the thought in spontaneous speech. (Mccrum, 1998, p. 195)

The advantage of using text [e-mail], as many of us agree, is that we can write as ideas come and keep coming back to re-edit until we are satisfied about the context and content of our messages. (Truscott, 2003, p. 15)

I have started to write poetry. . . . The nice thing about poetry is that it really doesn't have to rhyme. . . . It doesn't need to have complete sentences or even words that fit together perfectly. (Truscott, 2004, p. 96)

Writing has definite advantages over speaking for expressing both inner and social voices. These benefits for the process of expression and for the outcomes are outlined in Table 2. The list of outcomes emerged largely from an earlier chapter concerning the benefits of older adults writing to and for their grandchildren compared to looking for opportunities to tell their stories directly to their grandchildren. (Ryan, Pearce, Anas, & Norris, 2004).

Compared with speech, writing leaves a record and can link people across distance and time. Writing reaches more than the immediate audience and can even be effective with no specific immediate recipient. Moreover, writing allows for depth of analysis and linkages with previous works. It also creates time for communicating educational messages through humor. For example, Becker (2004) was able to illustrate the poignancy

Table 2
Specific Benefits of the Written Social Voice

Process	Outcomes
Control	Stable/permanent
Flexible timing	Overcome geographical distance
Assistance invisible	Surpass time
Less reliance on good memory	Broader audience
No need for hearing or nonverbal cues	Greater depth
No specific recipient needed	Thoughtful use of humor
	Legacy

of her communication dilemmas in health encounters entertainingly via cartoon characters who made the assertive or aggressive responses she did not dare to use herself.

Bonnie Sherr Klein (1997), the well-known filmmaker, realized eventually that writing could be even more powerful than film, especially when including the filmmaker's focus on differing perspectives through the combination of her narrative and personal journal entries with commentaries about episodes by the major players.

Thomas DeBaggio (2003) articulated the meaning created within a life with dementia by writing out his legacy:

When I die nothing will be left except someone else's memory of me. Only these words of mine will remain to shred my life into moments I now quickly forget. (p. 19)

Conclusions

The model of Communication Predicaments of Disability in Figure 1 illustrates how individuals with disability can interrupt the negative feedback cycle of the predicament model through selective assertiveness. By selective assertiveness, we mean making choices to be assertive and selecting words and nonverbal behaviors that will allow achievement of both instrumental and social goals. Conversational assertiveness can be very challenging when an individual is feeling powerless and in the process of seeking a new identity. As argued here, writing can offer a way to develop the inner voice, sense of identity, and one's legitimate power. It can be a vehicle for reconstructing identity and finding a new voice, that is, empowerment.

Thus, writing can facilitate selective assertiveness throughout the experience of disability in a variety of ways. Through journaling, for example, one can write to find the key elements of assertiveness (calm, confidence in identity, clarity about issues, empathy for another's point of view, what to say). Once a person has something to say, writing offers control, away from the shaping power of the communication predicaments in conversation. Actually, writing offers the control usually associated

with powerful speech styles (Ng & Bradac, 1993). It is not dynamic or dependent on openings offered by others, as is assertiveness in conversation. Corresponding with others through e-mail or letters supports the development of both the inner and social voice (Truscott, 2003).

Authors with a disability have used their social voices to demonstrate the possibilities of the written modality for empowerment (see Ryan, Spykerman, & Anas, 2005). Writing for others is a meaning-making choice of response to their experiences. These writers, as Michalko (1998) has described in regard to blindness, have come to see their disabilities as eloquent teachers about self and about humanity. In terms of story, the wounded storyteller becomes a wounded healer through storytelling (Frank, 1995). Disability stories inspire others encountering disability to follow their own path from chaos to lessons learned. As Frank (1993) has pointed out, these stories can “serve as valuable open-ended resources (i.e., ‘so you see what happened to me’), rather than prescriptions about what will happen to you and what you should do about it” (p. 49). Such survival narratives also enable readers in good health to face the reality of their own vulnerability as a part of the human condition. Finally, these disability memoirs offer a way to individualize members of a marginalized group: putting faces on disability, giving voices to disability that lead recipients beyond stereotypes and self-protection through the power of story.

Will the morning bring me power?
Or will the morning bring me pain?
Do not tell me of the hour,
I have only time to gain.
At the darkest point of night
I have only to gain light. . . .
And we awoke to promises
of sun:
red glints on the wall
and the call of an owl. (Bradac, 1995, pp. 24-25)

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