

Concerns and Considerations in Mental Health Practice with Older Culturally Deaf Adults

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Abstract

The elderly population in America is expected to more than double over the next half century. Consequently, the corresponding growth of the culturally Deaf¹ elderly population becomes important to examine. Because this population is a subgroup of both the hearing elderly and culturally Deaf populations, the expectation is that mental health professionals working with Deaf elderly clients will have specific concerns and will behave in ways that are specific to this population. Little is known, however, about the issues that challenge mental health professionals working with elderly Deaf clients. At present, mental health professions across all fields are unprepared to provide competent and quality services to the growing numbers of elderly Deaf clients.

This review attempts to shed some light on this unique population, while at the same time, point out the cultural differences critical to providing best quality of services from mental health professionals. The need for more current and applicable research is also explored, with emphasis on the elderly Deaf as an underserved and under-researched population.

One of the fastest growing populations in the United States today is that of people over the age of 65. The term *elderly* is most often defined as describing those people ages 65 and older (National Institute on Aging, 2002). According to the 2000 census, about 38 million elderly people live in the United States (U.S. Bureau of the Census, 2002). Current estimates suggest that, by the year 2020, over 53 million people living in the United States will be classified as elderly and by 2030, 20% of U.S. citizens will be over 65 years old (U.S. Bureau of the Census, 2002).

¹ "The use of Deaf for culturally Deaf and deaf for audiologically deaf is now standard in the field of deafness" (Glickman, 2003). "The capitalization of the word 'Deaf' is often used to denote an identification of an individual with the Deaf community. This implies a linguistic and cultural understanding, and comfort in being identified as Deaf" (Paul, 1993). "The use of the term Deaf in this context carries no stigma of impairment and allows for sociocultural discussion" (Reagan, 1990).

Along with these projections related to the elderly population in general are projections specific to elderly persons who are deaf and hard of hearing. Population statistics published by the Gallaudet Research Institute (GRI) in 1994 suggest that the elderly deaf and hard of hearing population totaled more than 11 million and made up about 29.1% of the population of all elderly people in the United States (Holt & Hottel, 1994). In a 1989 study the Gallaudet Research Institute predicted that the demand for services by elderly deaf and hard of hearing people will continue to grow, exceeding both the current demand for services and what is currently available (Brown, Hotchkiss, Allen, Schien, & Adams, 1989; Hotchkiss, 1989).

In past decades, the typical attitude of hearing people toward Deaf people was devaluative and discriminatory, causing Deaf people to feel inadequate and inferior (Sussman, 1976). Deafness was viewed as a pathologic condition to be corrected by acquiring skills designed to achieve the goal of imitating the majority (i.e. speech/lip reading, hearing aids; Gulati, 2003; Lane, 1990; Rosen, 1986). Attitudes that influenced perceptions of deafness in years past may still have an effect on elderly Deaf people today. Many Deaf people who currently would be considered elderly probably functioned during their developmental and adult years as outsiders in the hearing world, and as members of an "inferior" group, similar to other minority groups (Higgins, 1980; Marschark, 1993). Early publications on deafness (Mykelbust, 1950; Peet, 1856) show an adherence to this idea, reflecting how deafness has been long viewed by various professions and probably by hearing people in general. These earlier views would have most affected today's elderly Deaf people, their parents and grandparents, and past generations of the general public who grew up and were educated on using these types of portrayals.

How does the culturally Deaf elderly person see him- or herself fitting in with the Deaf community, and how does the Deaf community view the elderly Deaf person? Although few studies explore this issue, sources of information and interviews with elderly Deaf people seem to suggest that elderly Deaf people see themselves as an important and valuable part of the Deaf community, and as part of the preservation of Deaf culture. Elderly Deaf people typically serve a role as storytellers or cultural historians. They may educate others about the roots of Deaf culture and American Sign Language. Though often less educated and "worldly" than more modern and younger Deaf adults (which might be explained by the lack of available assistive technology and supportive

legislation for their generation), elderly Deaf people feel they still serve a purpose in today's Deaf community (Lane, Bahan, Hoffmeister, 1996).

Lane, Bahan, and Hoffmeister (1996) give some insight into the "graying" Deaf generation compared with the younger generation of Deaf adults. They suggest that younger and older Deaf adults have different backgrounds. Traditionally, older Deaf men could find jobs only in the trades, in areas such as printing or carpentry. Deaf women were often homemakers or would sometimes take jobs related to sewing. Younger Deaf adults have experienced more educational opportunities, have had access to better and more varied resources, and have developed different interests than the Deaf people of previous generations. This has aided in the creation of a "Deaf professional middle class" (Lane, Hoffmeister, & Bahan, 1996). According to Lane, Bahan, and Hoffmeister (1996), despite their different backgrounds, younger members have always accorded elderly Deaf people special respect and have seen them as the repositories of Deaf history, with a long record of activism on behalf of the Deaf community. However, in a recent interview with an elderly Deaf woman conducted by the author, she commented, "Younger Deaf don't care about history ... they are too modern, too like hearing, just want to make money.... The Deaf community changed.... They [younger Deaf] don't care about us" (anonymous communication, 2003).

It is important for any professional working with Deaf individuals to be sensitive to and knowledgeable regarding the influence that culture has on the Deaf client (Glickman, 2003). Social and emotional development, as well as communication, may be important aspects to consider when providing mental health services (Glickman, 2003; Duffy, 1999). Communication variations among clients, the preferences of Deaf clients, and cultural considerations need to be taken into account (Harmer, 1999; Harvey, 1989). Additionally, some elderly deaf and hard of hearing people may feel a connection to the Deaf community and consider themselves to be culturally Deaf, even though they do not have complete mastery of ASL. This lack of native fluency may be a reflection of the environment in which they were raised (Lane, Hoffmeister, & Bahan, 1996; Becker, 1980). Likewise, some elderly deaf people may use sign language but do not feel a cultural or communal connection to the Deaf world (Pullen & Kyle, 1997).

While a fair amount of research has been done on mental health and Deafness, a significant gap seems to occur with respect to studies involving the elderly Deaf population. Clearly, elderly Deaf people are a significant and growing part of the Deaf community, however, little is

known about how they perceive mental health services or about how mental health professionals perceive them.

Currently, no federally funded, uniform, standardized, or formalized national program is providing services to or studying the culturally Deaf elderly population. Although a variety of organizations do provide some services, these organizations are often branches of Deaf social clubs or various service agencies designed to support either Deaf adults or deaf and hard of hearing populations. The majority of them are not specifically focused on elderly Deaf people (Lane, Hoffmeister, & Bahan, 1996; Becker, 1980). Pullen and Kyle (1997) express concern at the lack of available and appropriate services for elderly Deaf people and suggest that the Deaf community can be a great resource. However, they also point out that as one becomes older and less mobile, participation in community events may become more difficult.

Those providing services to Deaf elderly people often fit into one of three categories: (a) mental health professionals who have training in gerontology but little experience or ability to communicate directly with Deaf people, (b) members of the Deaf community (or individuals who have standing in the Deaf community) who have experience working with older Deaf people but lack academic or formal training in any mental health field (Lane, Hoffmeister, & Bahan, 1996; Paul & Jackson, 1993; Becker, 1980), and (c) newer mental health professionals who have training and communication skills in working with deaf people, but who have no training in the area of gerontology.

Sela (1986) surveyed senior centers and service providers to determine whether deaf and hard of hearing elderly people were being served and if so, to what extent. The results of this study revealed that only 9% of the service providers surveyed offered programs specifically designed for deaf and hard of hearing older adults. The formation of groups such as Self Help for Hard of Hearing People, Inc. (SHHH) and the creation of the National Institute on Deafness and Other Communication Disorders (NIDCD) have somewhat increased advocacy for elderly people with hearing loss; however, services are still lacking for those who are culturally Deaf and over the age of 65. One major complaint found among Deaf nursing home residents is expressed in the appeal by residents for more "Deaf people working here both days and nights ... who understand what I am saying" (Pullen & Kyle, 1997, p. 6).

The literature on mental health ethics and Deaf clients is limited and typically focuses on the challenges of working in a small community that is based on culture and language identity. Paul & Jackson (1993) and Leigh (2002) suggest that, although these challenges are important issues

that can lead to some very real problems for clinicians working in the Deaf community, other equally important issues have received less scrutiny.

No ethical guidelines have been articulated with respect to providing mental health services specifically to older Deaf clients, and few textbooks present information on ethics related to Deaf clients in general. Gutman (2002) cites several issues that are relevant for the mental health professional working with Deaf clients, including particular confidentiality and privacy issues, communication competency issues, and issues with respect to appropriate training.

Literature on the elderly Deaf population is practically nonexistent. Pray (2002) states that "when mental health professionals discuss issues specific to counseling and psychotherapy with deaf and hard-of-hearing people, older clients are not typically a major focus." However, as the population of Deaf people and elderly Deaf people grows, so too will the need for mental health professionals with special training in working with culturally Deaf elderly clients. Pray (2002) suggests that the mental health professional working with the elderly Deaf client will find some ethical issues that arise frequently, possibly as a result of cultural differences between Deaf and hearing populations. Additionally, Pray (2002) states that:

"Ethical issues, dilemmas, and conflicts in practice with older deaf and hard-of-hearing people arise within the context of societal attitudes, the personal values and attitudes of the professional, and professional values and ethics articulated in the codes of ethics of professions such as counseling, medicine, nursing, psychology, and social work."

The relationship between the client and the mental health professional is bound by ethical guidelines, which provide a framework that assists professionals in making ethical decisions during their interactions with clients. As with other unique and vulnerable populations (e.g., children, persons who are mentally ill, and prisoners) these guidelines can become unclear, and sometimes impractical, when working with elderly clientele. The American Psychological Association (APA) guidelines on ethical behavior (APA, 1992, 2003) covers many issues related to professional relationships, as does the National Association of Social Workers (NASW, 1999) and the American Counseling Association (ACA, 1997). Although these guidelines are

generally clear and practical for younger adult populations, they may sometimes become blurred or impractical when working with an elderly population.

For example, one ethical issue to consider is that of professional competence (see APA Code Section 1.04a, APA, 1994, 2003). Does the psychologist or other mental health professional have the education and experience to effectively work with the population in question? This is important when working with elderly Deaf people because this particular group has characteristics that are unique related to age, communication, and other cohort-related factors. Additionally, Glickman (2003b) suggests that, often, agencies and mental health programs take the term *competence* too lightly and refer to a staff member who knows a few signs as a deafness expert. In addition to having competence in working with elderly Deaf clientele, the psychologist or other mental health professional must also have training for practicing with elderly clientele in general, and a concern for their welfare, both as individuals and as a group (Cantor, Bennet, Jones, & Nagy, 1994).

The elderly client may have several caregivers at a time, including his or her children or other relatives, guardians, health-care providers, or state agencies, some of whom may be making many of the client's decisions and, thus, affecting the autonomy of the client (Belsky, 1990). The needs and priorities of the elderly client's family, his or her nursing home staff, his or her medical doctor, and various personnel in state, county, or city agencies may directly conflict with the needs and concerns of the client (Greene, Adelman, & Rizzo, 1998; Burgio & Sinnott, 1989). For example, while Lauber & Drevenstedt (1993) found that older clients tend to prefer older therapists, Sinnott, Burgio, & Lakein (1998) found that the families of elderly people often prefer that their elderly family member have a younger psychologist or other mental health professional with whom the family can more easily communicate. Here, we see a direct conflict between what the family may want and what the elderly client desires.

For a Deaf person, the issues of family and community are typically a significant part of Deaf culture (Gulati, 2003; Lane, Hoffmeister & Bahan, 1996; Paul & Jackson, 1993). As a Deaf person becomes older, these community and family bonds are likely to become even more important, because few social service or mental health agencies are equipped to handle his or her unique needs (Paul & Jackson, 1993). Although an elderly Deaf person may still have several caregivers, he or she may, depending on the availability of services, be able to directly communicate with only a few of them. Caregivers who

can communicate in sign language/ASL will often be family members. Additionally, in situations where the elderly Deaf person has a hearing family, family members may not be effective in determining and supporting the Deaf elder's wishes. Because few mental health professionals can directly communicate with elderly Deaf clients, some intermediary for communication, such as a sign language interpreter or a family member, will likely need to be provided. As mentioned above, elderly hearing clients generally prefer older professionals to whom they feel they can relate. However, elderly Deaf clients may prefer professionals with whom they can communicate directly using sign language, regardless of age.

Although many of the ethical guidelines covering research are intended to protect any population, special and vulnerable populations require extra consideration when participating in research. In these situations, common ethical standards and practices apply in different, more restrictive, ways. In performing research with an elderly population, the researcher needs to consider how common ethical standards apply and affect the parameters of ethically responsible research with elderly subjects, many of whom may be vulnerable to exploitation, even if it is not intentional.

Ethical standards require that people may not be used as research participants without their consent. Consent by elderly people to serve as research participants meets the informed consent requirement only if the elderly individual has and exercises the capacity to decide whether or not to participate (Wicclair, 1994). This ethic assumes that the elderly individual understands the nature of the research, meaning he or she has been informed of, and understands, any possible harm or benefit that may come from being a participant.

Ensuring Deaf study participants' right to informed consent may also require greater emphasis and effort than ensuring these rights with a hearing population. Communication must be effective, so the Deaf participant is able to comprehend the essential elements of informed consent (Pollard, 2002). Harmer (1999) notes that the "literacy level of consent forms or other written materials should be a first consideration." Consent forms alone will not be sufficient in "conveying the necessary information to yield informed consent," and "informed consent conversations" are imperative (Pollard, 2002).

It has been suggested that Deaf people who are born deaf or have been deaf most of their lives manifest a certain degree of adjustment that develops throughout life in response to stigma, discrimination, social isolation, and deafness (Becker, 1980; Tidball, 1986). Although this kind

of adjustment does not imply an inability to age successfully, it does suggest that cohort effects, as well as history of the individual and community, should be examined when discussing client behavior. Because many of today's elderly Deaf people grew up without ADA accommodations and experienced a greater degree of paternalism, they may have difficulty comfortably expressing their desires and preferences. Many elderly Deaf people who grew up in circumstances different than today may sustain an underlying acceptance of doing what they are told, especially by hearing professionals or authority figures. Earlier developmental experiences may shape the perceptions of elderly Deaf clients who may have grown up with paternalistic portrayals and childlike illustrations of Deaf people (Feldman, 2004).

Finally, when conducting research of a sensitive nature, the researcher needs to have recovery and referral plans in place for a debriefing process to address any emotional reactions the participants may have. To bring up sensitive and stressful issues without having some kind of support in place for the participants would be unethical and irresponsible. Questioning an elderly person on loneliness or family issues may cause emotional distress, and to deal with these problems, the researcher needs to have professionals available who are competent in working with elderly subjects (Belsky, 1990; Knight, 1996). The researcher working with the elderly population should be aware of the many emotional stressors that affect elderly people, and have knowledge of treatment options (Russell, 1999).

In addition to the above issues, mental health professionals working with Deaf clients have other concerns with respect to ethics and deafness. Pollard (1998) suggests that lack of ambient auditory information, which is not accessible to Deaf participants, may lead to an unintended form of deception. Brauer, Braden, Pollard, & Hardy-Braz (1998) note the cognitive and linguistic variance among Deaf subjects arises from "differing degrees of access of overheard conversation, radios, and other auditory information, as well as differences in literacy." Both of these issues may be even more important when working with elderly Deaf participants, due to cohort effects, such as less access to media and education during their developmental years. Pollard (2002) also points out that because the Deaf community is small, the preservation of anonymity is problematic. Research on Deaf individuals often involves a "participant pool with much greater interpersonal familiarity than with hearing participants." Additionally, Deaf members of the research team, especially those active in the Deaf community, may add to the problem of keeping Deaf subjects anonymous (Pollard, 2002).

The mental health professional working with an elderly Deaf client may find him- or herself involved in both non-professional, and professional roles with clients, grandchildren, and other family members, as well as the Deaf community at large.

In the past, Deaf workers have had less employment opportunities and have earned less than their hearing counterparts (Lane, Hoffmeister, & Bahan, 1996). This situation puts the elderly person at risk for mental health problems for two reasons. First, the poor and elderly Deaf person may not be financially able to afford important goods and services such as recreation, entertainment, transportation, or education. These activities are often considered necessary for mental health, social status, avoidance of isolation, and personal growth (Butler, Lewis, & Sunderland, 1998). Second, the elderly Deaf person who has a mental health problem might not be able to afford the costs of treatment which may not be covered, or may be only partially covered, by medical insurance.

With the passing of the 1973 Rehabilitation Act (PL 93-112) and the 1990 Americans with Disabilities Act (PL 101-336), some of the barriers in the workplace were removed and legal protection was extended to people with disabilities at work sites (Lane, Hoffmeister, & Bahan, 1996). The increase in accessibility in the work place led to a shift in the economic status of Deaf people and created an economic base greater than they had previously experienced. However, this shift applied primarily to younger Deaf people and had little effect on older Deaf people and those closer to retirement. This older group, who make up much of today's elderly Deaf population, worked primarily in manual labor, low-skill jobs, and jobs providing low-to-moderate pay, all of which offered little or no protection against exploitation (Lane, Hoffmeister, & Bahan, 1996). Consequently, many in this older group were not able to effectively save any significant amount for their retirement and are restricted to whatever benefits or pensions for which they qualify.

If the elderly Deaf adult is financially able to participate in mental health services, many health insurance or Health Management Organizations (HMOs) have a specific list of mental health professionals from which a consumer is allowed to receive services, which also applies to Medicare Supplemental Coverage (DHHS, 2002). These HMO lists typically contain a majority of professionals who do not know sign language, have no training in working with elderly Deaf clients, or lack critical skills in both of these areas. Because HMO lists dictate who is eligible to receive reimbursement from the HMO, clients may not have

Thompson for Presentation
- Etiology
- Age of onset
- degree of loss - effort
of incidental learning

access to a professional who signs, or a trained professional specific to their needs as elderly Deaf people. While there are ways to work with HMO's to add professionals' names to these lists, in most circumstances this can be a lengthy process and requiring both the professional and the client to know a great deal about the HMO system.

Another issue that is typically relevant when working with older adults is that of suicide and euthanasia. The American Psychological Association (APA), among other professional organizations, has clear standards on issues of suicide. By law, the psychologist is required to protect a patient, which may include breaking confidentiality and making a report to the police or a family member (see APA code section 5.05a, APA, 1992, 2003). In most circumstances, breaking confidentiality is accepted, for obvious reasons, as the most responsible and appropriate action. However, debate continues regarding both suicide and euthanasia, in terms of the ethics of not preventing, through action or inaction, the death of an elderly client who wishes to die.

Typically, the psychologist, or other mental health professional has a minimal role in the actual decision or actions of the elderly client who wishes to die, or of the family member or guardian who wishes to assist (Butler et al., 1998). More often, the role of the psychologist during these times is to provide a "safe environment" for the elderly client, the client's family, or the client's guardian to discuss their feelings, wants, or needs (Abeles, Cooley, Dretch, Harper, Hinrichsen, Lopez, & Molinari, 1998). The psychologist or other mental health professional may be asked or relied on to provide assistance in helping the elderly client cope with his or her suicidal feelings, or to help the family cope with a consideration of euthanasia (either "active" or "passive"). With younger clients and the caregivers of younger clients, the psychologist or other mental health professional is required to protect the client, which may include informing medical personnel, family members, or even the authorities of suicidal ideation or potential harm to another person (Abeles, et al., 1998). The American Psychological Association makes no exception for these circumstances when they occur with elderly clients or their families (APA, 1992).

The close-knit tradition of the Deaf community and its emphasis on familial importance may complicate matters for the practitioner working within the Deaf community. Contacting agencies that are typically not part of the Deaf community can place the mental health professional in a difficult situation. Reporting suicidal ideation, or the family's support of suicide (elder abuse), though still mandatory under state or federal law, might be made more difficult if the participants were

known by the practitioner, who may also be part of the Deaf community. The practitioner may know the family and friends of the people involved in an abusive situation, making it more difficult to report abuse allegations to authorities. Although the provider may have taken the correct action professionally and legally, the question remains as to what happens to the practitioner's standing in the Deaf community, especially if the reports turn out to be false.

Questions may also arise regarding who should be involved in the social or family problems of people in the Deaf community (Gutman, 2002; Lane, 1996). Is it better to report elder abuse, suicidal individuals, and homicidal threats to hearing medical or mental health professionals, family members, or authorities who may have little or no experience with elderly Deaf people? These individuals rarely have the ability to effectively communicate with an older Deaf person. Or, should the Deaf community handle its own problems from a perspective more sympathetic and understanding of deafness and the cultural aspects of the Deaf community? Should a Deaf person who is contemplating suicide be placed in a hearing hospital, isolated, and attended by staff members with whom he or she cannot communicate, or should the elderly Deaf person be placed with non-medical/mental health professionals, or Deaf family and friends, watched over, and given whatever outpatient treatment is available by professionals trained to work with Deaf people? These questions are not meant to imply that one way is necessarily better than another, or that APA Ethical Guidelines should not be followed. Instead, they pose issues that a practitioner working in the Deaf community may be forced to consider during a patient crisis, and may need to further reflect on in terms of how these considerations may affect the behaviors of the practitioner.

There are more questions than answers related to mental health and elderly Deaf clients. As mentioned above, few research studies have focused on this population, and few academic programs in mental health or gerontology identify the elderly Deaf as even a minor training focus. Among these questions are: what are the needs, wants, and perceptions of the elderly Deaf adult specifically related to mental health? How does a mentally healthy, or unhealthy, elderly Deaf person appear on diagnostic measures or psychological testing, especially considering that so few measures exist to accurately evaluate Deaf people in general? Even fewer are designed for use with elderly Deaf participants. Finally, what can mental health professionals practicing with Deaf clients do to better prepare for the growth of the elderly Deaf client population? There is a need for more trained professionals with both geriatric and

deaf specialties across all mental health professions. The body of research in a number of areas (demographics, preferences, cognitive functioning) needs to be expanded to better understand this population. This should include not only the perspective of the mental health professional, but those who are elderly and Deaf, and of the Deaf community as a whole, as it is likely this community will bear at least some responsibility and active involvement in the care of the elderly members of their community. Certainly, this should not be done in a vacuum. There does exist a fairly large, though by no means complete, body of literature on Deaf people in general. The initial study of elderly Deaf people may need to involve some of these resources, if for nothing else as a starting or reference point. However, it should be kept in the mind of the researcher that the elderly Deaf adult grew up in a very different social environment than his or her younger counterparts of today. Lastly, the elderly, Deaf or hearing, are a special population. In the same way we are told not to look at children as "short adults," we must not simply look at the elderly as "gray adults." The mental health professional should ultimately attempt to understand the older Deaf adult in the context of his or her experiences and their relationship to the aging process. By achieving these things, the mental health professional will likely be better prepared for, and more competent to treat the elderly Deaf client.

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Communication and Mental Health Issues

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Abstract

Social work and mental health clinicians recognize the importance of adequate communication in work with clients who are deaf and hard-of-hearing. A three-year research study examined the experiences of deaf and hard-of-hearing individuals who had been in psychotherapy. This grounded-theory approach identified five major areas of concern: accessibility to culturally sensitive therapists, communication processes, issues of confidentiality, the use of the social work/therapeutic relationship as well as culturally specific interventions in work with deaf and hard-of-hearing individuals. A detailed description of the research study, population, methods, and data analysis can be found in the article entitled *Perceptions of the consumer*, published in JADARA 2002, 36(1). Consumers of psychotherapy emphasized the importance of communication, not only related to the mechanics of communicating (use of interpreter, linguistic matching) but the cultural and psychological processes inherent in the communication process.

Introduction

Individuals with hearing loss adopt diverse communication strategies and coping mechanisms to manage the hearing loss. Individuals who are born deaf or who have become deaf early in life may have little or no usable hearing with which to understand spoken language, and thus do not learn how to develop intelligible speech. Individuals who become deafened after spoken language acquisition may be able to retain speech and English language skills. The severity of the hearing loss is important to the development of speech. For example, individuals who do not have any residual hearing will probably be able to speech-read only 30% of all spoken language, thereby making oral communication tedious at best. Depending on the individual, the degree of hearing loss, and its impact on one's functional abilities, those who lose their hearing later in life may mitigate those losses with the aid of technology and medical adaptations (e.g., cochlear implants, hearing aids, loop systems) in order to function in the hearing world. Most of these individuals view their hearing loss as a disability and a tragedy.

Individuals who belong to the Deaf community experience common socialization experiences: learning about their Deaf social

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