

Research

Nominal Group Technique: An Accessible and Interactive Method for Conceptualizing the Sexual Self-Advocacy of Adults with Intellectual and Developmental Disabilities



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Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities

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Abstract

People with intellectual and developmental disabilities (IDD) must often advocate for themselves in many facets of life, including sexuality. Because of this, sexual self-advocacy is an important concept to develop and apply to policy and practice. This paper provides a conceptualization of *sexual self-advocacy*, a view of sexuality formulated by adults with IDD that is closely tied to the values of the Self-Advocacy Movement. In describing the study process, this paper also puts forth the Participatory Action Research method Nominal Group Technique (NGT) as an accessible method for gaining insight from adults with IDD. The choice of Nominal Group Technique as a research method was motivated by several factors. NGT served to counterbalance many of the potential research difficulties when working with people with IDD, including the need for understandable, inclusive and participatory ways to access data from people with IDD, and addressed the topic of *sexual self-advocacy* that is important to people with IDD.

Keywords

Nominal Group Technique, Participatory Action Research, intellectual and developmental disabilities, sexuality, methodology, self-determination

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Introduction

Self-Advocacy is a social and political movement of people with intellectual and developmental disabilities¹ (IDD). People with IDD involved in the movement (self-advocates) describe Self-Advocacy as

independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in. (Hayden & Nelis, 2002, p. 221)

Self-Advocacy serves as both an avenue to empower people with IDD and a form of resistance against discrimination and oppression (Buchanan and Walmsley, 2006; Caldwell, 2011; [citation removed for blind review], 2014). While Self-Advocacy can produce deeper senses of community, culture, identity formation, and disability pride (Caldwell, 2011; Carlson, 2010; [citation removed for blind review], 2014), it is also noted for its liberatory potential because it directly challenges deficit-based understandings of IDD by continually pushing for self-determination. While there are various definitions of self-determination, self-advocates define self-determination as making themselves heard about their wants and needs, including both daily decisions and larger goals (Nonnemacher and Bambara, 2011). Interdependence is a

¹ IDD is the most appropriate terminology in the United States to describe the more general categories of *developmental* disability, which refers to “a severe or chronic condition that is acquired before age 22” (Altman, 2001: 99), and *intellectual* disability, which describes “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (Schalock et al., 2007: 118). The terms ‘intellectual disability’ and/or ‘intellectual and developmental disabilities’ have replaced historical terms such as mental retardation in literature, advocacy, and federal statutes (Schalock et al., 2007).

core aspect of self-determination for people with IDD because they often rely on other people in their lives to provide support so they can enact their self-determination (Wehmeyer, 1998).

Researching sexuality and people with IDD

While many advances have been made regarding the quality of life for people with IDD, including increased access to community services, supported employment, and the growth of the Self-Advocacy movement, people with IDD are still often perceived as both hypersexual and asexual, stripped of their identities as sexual beings, and viewed as lacking capacity to consent to sexual relationships (Milligan and Neufeldt, 2001; Murphy and O'Callaghan, 2004).

Research on sexuality in people with IDD has undergone several shifts. During the 1970s and 1980s, the literature on the sexuality of adults with IDD tended to focus on managing, controlling, and limiting sexuality (Bernert, 2011), with prominent narratives of men with IDD as potential aggressors and women with IDD as potential victims emerging (McCarthy, 2014). More recently, the literature has focused on the sexual experiences and sexual identities of adults with IDD, with an emphasis on personal agency, autonomy, and choice (Azzopardi-Lane and Callus, 2014; Bernert, 2011; McCarthy, 2014; Swango-Wilson, 2010; Taylor Gomez, 2012). Much of this literature has used questionnaires and individual interviews, augmented by focus groups as a way of member checking (Bernert and Ogletree, 2013; Bernert, 2011; Eastgate et al., 2011; Lafferty, McConkey, and Taggart, 2013). While in many ways this literature has advanced the role of people with IDD in research, the unit of analysis has overwhelmingly been the individual, instead of group processes and dynamics.

Because of power imbalances, people with IDD must often advocate regarding their sexuality, forcing them to engage with other people, particularly authority figures, in ways that nondisabled people do not experience. For example, adults with IDD who live in in group homes

often have to negotiate getting private time with their significant other. Thus, sexual self-advocacy is an important concept to develop and apply to policy and practice because it provides opportunities to address relational and structural power inequalities. While the Self-Advocacy Movement has provided a space for adults with IDD to speak up for themselves and their friends, sexual self-advocacy has been defined as people with IDD speaking up for their rights and getting the information and support to increase their sexual consent capacity (Moras, 2011).

Methodological challenges of doing research with adults with IDD

People with IDD have only recently been considered reliable sources of research data (Emerson et al., 2013). Prior to the 1980s, data about people with IDD was obtained through proxy research, which asked family members and professionals to report instead of asking people with IDD (Emerson et al., 2013; Ward and Simons, 1998). Proxy research is problematic because people with IDD have unique perceptions, experiences, and understandings to which family members and professionals may not have access (Carlson, 2010; Emerson et al., 2013). Since the 1980s, it is more common for people with disabilities to be research participants and informants about their own lives (Chappell, 2000). However, research methodology has not always kept up with sociopolitical advances for people with IDD. Some researchers who work with adults with IDD have called for new methods to improve interaction, reduce difficulties, and strengthen research (Caldwell, 2013; McDonald et al., 2013). To answer the current research question, we turned to Nominal Group Technique (NGT) as an accessible research method.

Purpose

Because sexuality has different meanings depending on disciplinary and professional bases (e.g., sexuality as an aspect of health (Lindau et al., 2007), dimension of identity (Bernstein and Taylor, 2005), or as a part of human relationships (Christopher and Sprecher,

2000)) the present study used the conceptual framework of the IDD Self-Advocacy movement as a way to connect the more generalized notion of sexuality to a more concrete and specific concept of *sexual self-advocacy*. Using NGT as a method, this exploratory study asked people with IDD what sexual self-advocacy meant to *them*. Many aspects of our research design, including conceptual framework, method, and data analysis were guided by the core themes of the Self-Advocacy movement, including self-determination and interdependence. Sexual self-advocacy as an applied concept may also be a politically expedient tool that people with IDD can use to advocate for change.

Unlike other sexuality research that used formal individual interviews, Azzopardi-Lane and Callus's (2014) study investigated how members of a Self-Advocacy group viewed sexuality and relationships. The authors used Self-Advocacy group discussions as their unit of analysis. This paper builds on Azzopardi-Lane and Callus's (2014) use of group process methods by putting forth the Participatory Action Research (PAR) method NGT as an accessible method for gaining insight from adults with IDD. As there is very little research on sexuality of people with IDD in relation to the Self-Advocacy movement, this research study asked how participants defined sexual self-advocacy.

Sexual Self-Advocacy study: An application of NGT

In keeping with the Self-Advocacy movement's emphasis on self-determination, interdependence, and advocacy, our PAR study used NGT, a structured group discussion aimed at brainstorming and problem solving (Tuffrey-Wijne et al., 2007; Van de Ven and Delbecq, 1974). Within NGT, participants are first given a topic or question and then are given time to independently brainstorm and write their ideas down. Participants then share their individual ideas with the rest of the group in a circular manner, with each participant sharing one idea at a

time. As they do so, these ideas are written down by a facilitator for the group to see, often on a wall or blackboard. Similar ideas are combined into themes as the participants share so the final list shows all the discrete ideas generated. After all ideas have been shared, the group participates in a discussion about the themes and some ideas may be re-sorted based on the group feedback. Each group member then independently votes to rank the themes, representing the group's prioritized themes. The results include both quantitative rankings and qualitative ideas.

NGT has been used with diverse populations (Carney et al., 1996; Chapple and Murphy, 1996; Lloyd et al., 1999; etc.), including those with a range of disabilities (Berry et al., 2011; Elliott and Shewchuk, 2002; Porter, 2012; etc.). Research that uses NGT with people with IDD, however, is very limited. Nevertheless, the studies described below demonstrate that complicated, difficult, and often-taboo topics have been addressed with people with IDD in NGT settings. Bostwick and Foss (1981) used NGT to determine people with IDD's community living barriers. Tuffrey-Wijne et al. (2007) used NGT to explore difficult end-of-life issues with people with IDD. Roeden et al. (2011) used NGT with people with IDD to examine the client-caregiver relationship. While studying people with IDD who have friends or family with cancer, Tuffrey-Wijne et al. (2012) used NGT in focus groups. Finally, Tuffrey-Wijne (2013) used NGT to study disclosure of bad news to people with IDD. The present study seeks to build upon and expand this body of literature by providing detailed information about how NGT was used with people with IDD.

NGT was appropriate for the scale and scope of this study's research question, and had the added benefit of enacting the values of the Self-Advocacy movement. Although it is efficient in terms of time, and the amount and quality of data produced was important, equally important

was the NGT's emancipatory potential (Cocks and Cockram, 1995; Tuffrey-Wijne et al., 2007). These benefits will be discussed in greater detail below.

Process

This research was completed during an all day community research forum in Chicago. The community research forum was planned collaboratively with a four-person research team (the authors of this paper) – two Ph.D. candidates, a community educator, and a clinical professor – and two people with IDD who represented two different statewide community advocacy groups. Adults with IDD were recruited to participate through word of mouth, advocacy organizations, and service providers. Thirty-five male and female participants attended, about 50% of who were people of color.

On the day of the forum, self-advocates participated in activities about sexual self-advocacy, NGT, and a closing circle process. The activities prior to the NGT included relationship and safety role-playing scenarios in addition to a short presentation on the sexual bill of rights for people with disabilities (Illinois Imagines, 2014). The purpose of these activities was to educate self-advocates to ensure that they understood the question asked during NGT. This practice has been used both in other NGT contexts (Van de Ven and Delbecq, 1974) as well as in other research with people with IDD (McDonald, 2012). We received ethical approval from the Institutional Review Board at our university. A licensed mental health professional was also on-call for any participant that wanted counseling.

NGT was introduced as a time for everyone to share their ideas and then discuss those ideas as a group. During NGT, participants were asked: 'What does sexual self-advocacy mean to you?' During the initial brainstorming period, which lasted about seven minutes, participants wrote down or drew their responses, with assistance from support people if necessary. The

support people were given specific instructions not to influence the responses of the participants, but to merely support participants in writing down their ideas. Drawn ideas were an accommodation that the research team had decided upon; usually NGT participants only write their ideas.

The facilitator announced that it was time for each participant to share one idea. Participants had the option of saying their idea out loud or having a support person say it on their behalf. If participants' written ideas were not clear (e.g., only said 'harassment'), the facilitator would ask them "What do you mean by that? Can you say more?" This prompting was often successful in clarifying ideas, resulting in responses such as, "Like when someone touches you and you don't want it." NGT uses an open-ended question approach, while providing structural support. Compared to close-ended questions, open-ended questions are less susceptible to acquiescence bias in people with IDD and result in lower levels of response error (Finlay and Lyons, 2001). Open-ended questions also produce greater recall (Finlay and Lyons, 2001). People with IDD also enjoy the opportunity to freely discussing their opinions via open-ended questions (McDonald, 2012).

As ideas were shared, two research team members grouped the written ideas by themes. This was done so themes could later be prioritized. When all participants had voiced their first ideas, we started from the beginning and had each participant share their second idea; the same happened with their third. Examples of participants' responses include "Being comfortable with other people," "Respect others girlfriends about sex (*sic*)," and "I have the right to have my opinions...I have the right to have privacy when I want" ([citation removed for blind review], 2014, p. 524).

After the participants all shared their ideas, participants were presented with the themes and asked if they agreed with the themes and if anything was missing. Participants added a few more ideas but agreed the themes were valid. In the final step participants ranked their top three themes. Participants were given three sticker dots to use in voting and they could vote multiple times on one theme or spread their votes among the themes. Once the votes had been tallied by the facilitator and several assistants, the top-ranked themes were announced. Spontaneous applause erupted after the theme with the most votes, 'my choices,' was announced. From the feedback given during the circle process after the NGT, at least several participants experienced a sense of accomplishment at the end of the NGT.

Analysis

As NGT is a mixed methods approach, rankings were calculated by summing the number of votes and the qualitative data were analyzed using inductive content analysis using the constant comparison method (Glaser, 1992; Van de Ven and Delbecq, 1974). The constant comparison method² involves examining patterns and creating and testing categories (Glaser, 1992), aided by theoretical sampling, which describes a roadmap for data collection and analysis (Boeije, 2002). Our theoretical sample was "Self-Advocacy." We had two strands of data analysis. The first group was the discrete ideas and the *in situ* themes that were generated during the NGT. The second strand of data was the transcript of the NGT that was coded independently by each research team member, which strengthened inter-rater reliability. Inter-rater reliability is often used within qualitative research to describe a general sense that group analysis is improved by individual independent analysis as well as group discussions (Armstrong et al., 1997).

² See Boeije (2002) for in depth explanation on how to carry out the constant comparison method.

The coded transcript added richness because it included not only the NGT results, but other conversations that happened *as a result* of the NGT process. While the themes within each strand were compared to one another, we also compared across strands, particularly focusing on how the themes related to each other. One benefit of the constant comparison method of analysis is that it allows comparison both within data groups and across data groups (Goetz and LeCompte, 1981) making it appropriate for our study, as we analyzed our data sources separately and then compared themes from each data strand with each other.

During four meetings, the four-person research team came to consensus on any discrepancies or differences between themes. Member checking, which involves bringing interpreted data back to the participants to have them confirm credibility (Creswell and Miller, 2010), strengthened the study's validity. Two participants who attended the community research forum examined the resulting themes as a form of member checking; they both agreed our findings mirrored the narratives and themes discussed by participants at the forum.

Study findings

Because Self-Advocacy was our theoretical sample, our themes are in accord with the tenets of self-advocacy. These themes, applied to the realm of sexuality, demonstrate both the relationship between people with IDD's concepts of sexuality and Self-Advocacy, and relationships between the themes themselves. Seven themes emerged from the NGT: knowing and respecting myself; respect for others; my choices; speaking up; respect my rights; getting information; and, healthy relationships. These themes are discussed in depth in [citation removed for blind review] (2014).

We divided the substantive themes into two "macro strands": 'communication' and 'respect.' A way of enacting sexual self-advocacy, communication is a reciprocal act where

people with IDD learn to speak up while others, such as those who have historically had most of the power, learn to actually listen. Our research forum exemplified the potential for empowering methods of communication.

Communication encompassed three themes: *speaking up*, *getting information*, and *healthy relationships*. *Speaking up* is about advocating for oneself and others. An important aspect of this theme was continuing to speak up even under pressure. For example, to one participant this included having the right to “not feel like a victim when you’re saying something important...don’t judge or discredit my opinions.” *Getting information* was also an important part of sexual self-advocacy. This included information about sex, relationships, and safety. One participant said, “how to ask someone out.” People with IDD often experience disparities in sexual education. As discussed above, people with IDD are commonly portrayed as asexual or hypersexual (Milligan and Neufeldt, 2001). These assumptions and fears often lead to the withholding of sexuality information from people with IDD. The third theme in this strand, *healthy relationships*, values communication and mutual respect between partners. When a relationship is healthy, self-advocates feel comfortable, loved, happy, and successful. They accept responsibility and express their sexuality in safe and healthy ways.

The second thematic strand is *respect*; this strand included the themes: *respect for others*; *knowing and respecting myself*; and *respect my rights*. *Respect for others* is about respecting other people’s beliefs and expressions of sexuality. This theme emphasizes that healthy relationships are reciprocal and based on mutual respect. Examples of participants’ responses that were coded as *respect for others* are: “respect other people’s wishes in a relationship” and “being respectful of others’ sexuality in a healthy way.” The second theme in the respect strand, *knowing and respecting myself*, included the goal of some level of self-concept in terms of

wants, needs, and identity as well as learning to love oneself. This means living up to the standards one sets for oneself as well as feeling comfortable expressing them to others. One participant said that sexual self-advocacy was “being comfortable with myself;” another participant emphasized, “telling someone what you want and what you don’t want.” Another crucial theme under this strand was *respect my rights*. This theme included not only being respected in relationships but to not be infantilized by the community at large. This also included their right to relationships, including same-sex ones, and sex.

At the hub of these themes, *my choices* emerged as central to sexual self-advocacy. This theme highlights that a large aspect of sexual self-advocacy is a person being able to make one’s own choices about what she or he wants and how one expresses one’s sexuality. Choices are unique to that individual and informed by one’s life experiences and values. The themes discussed above both align with and expand an understanding of self-advocacy that privileges self-determination and interdependence. Participants in this study emphasized respecting others and themselves, making choices that would benefit themselves and their partners, and claiming their rights to be sexual beings. This study adds to the definition of sexual self-advocacy by emphasizing choices, respect and healthy relationships as concrete ideal outcomes for adults with IDD. It also demonstrates that NGT, informed by self-determination and interdependence, can be used to maximize participation of people with IDD not only in research but in other life roles as well, most notably sexuality.

Discussion

The research team applied NGT, a PAR method, to a study that explored sexual self-advocacy, a conceptualization of sexuality by and for people with IDD that is closely affiliated with the Self-Advocacy movement. PAR methods are designed to empower people and improve

their lives by involving social minorities throughout the entire research process (Chappell, 2000; Nelson et al., 1998). PAR aims to create critical dialogue that privileges understudied perspectives and provides spaces where others can learn from diverse experiences and insights (Booth and Booth, 2003; Wang and Burris, 1997). This type of research not only recognizes people with disabilities as researchers, it also holds itself accountable to people with disabilities (Chappell, 2000). We used NGT for this study because it is accessible to research participants with IDD and because of its relationship with emancipation and self-determination, key components of Self-Advocacy and sexual self-advocacy.

While people with IDD are capable of participating in research without proxies (Emerson et al., 2013; McDonald, 2012), research with people with IDD is not without its challenges (Finlay and Lyons, 2002). NGT's design mitigates some of these challenges. People with IDD can have trouble answering questions about complex phenomena (Finlay and Lyons, 2001). NGT is an efficient method of generating many ideas about a single concept or idea, including the concept sexual self-advocacy, making it a beneficial method for working with people with IDD. Moreover, the data is expressed less as generalizations when participants have the time to think through ideas independently (Van de Ven and Delbecq, 1974).

One common assumption, often limiting participation in research, is that people with IDD are a homogenous group with similar opinions, experiences, and severities of impairments; however, the reverse is true (Carlson, 2010). NGT was developed for groups with mixed experiences and perspectives, and in this way our use of NGT aligns with the intended application of the method. For example, during NGT, participants in our study expressed a wide range of attitudes about when sexual relationships/activity is appropriate, with one participant saying "don't have sex before married," and another, "I can have sex with who I want." The

facilitator welcomed diverse and conflicting opinions during NGT, verbally reminding the group that everyone's opinion was respected. This diversity was not an issue during data analysis because divergent opinions often fell under the same themes; for example, participants who identified whether sexual relationships were appropriate were enacting the theme of "my choices."

NGT is a more accessible method for people with IDD because it is structured similar to familiar real world group discussions than other investigative methods (e.g., survey, one-on-one interviews). It is also inclusive of different communication styles because input is elicited in a low-pressure environment. For instance, if someone with IDD who is not typically given opportunities to voice his or her opinions does not feel comfortable speaking up in a group, his or her input can be included through written contributions. In our study some participants were not comfortable speaking in front of a large group and they were able to ask the support people or moderator to read their ideas to ensure their contribution was included.

As with all PAR methods, NGT is rooted in empowerment and designed with social justice in mind (Balcazar et al., 1998). NGT is a research method that has the potential to be emancipatory because it increases the role that people with IDD play within knowledge production about things that matter to them. The NGT is a method that aligns with the tenets of self-determination because it encourages the same skills including, for example, decision-making and problem-solving (Wehmeyer, 1998). Research methods that aim to be accessible for people with IDD should enact components of self-determination, which will also maximize participation.

Because of the collective history of disempowerment that people with IDD have experienced, it is important to attend to issues of power with research contexts. One issue with

one-on-one research methods is that they can intensify cultural scripts and power issues (Diefenbach, 2009). Cultural scripts and power issues are still present within group process research methods, but within the NGT, these issues are mitigated by the expectation of relationship building as well as an approach to power that has much in common with the Native American concept of “shared power,” which views power as unlimited, something that can be transferred and something that is an act of selfhood (Lowry and Mattaini, 1999).

The NGT strives to involve participants at all levels in the decision process (Delp et al., 1977); this is not the common experience for people with IDD who have not historically been an active part of research. People with IDD, however, have long been creatively speaking up for themselves and each other. One exchange between our participants demonstrates how navigating constraints is a part of sexual self-advocacy. One self-advocate said:

‘the doctor... looks at my staff and talks to my staff instead of looking at me and talking to me.’ Another self-advocate chimed in... ‘Doctors should talk to you not your staff.’ Another self-advocate also commented... ‘you can tell your staff not to go into the doctor’s office with you!’ Leading the original self-advocate to ask, ‘but what if you have no choice?’ and one of the other self-advocates to immediately shout, ‘you have a choice!’

A longer discussion about legal guardianship ensued, in which the phrase, ‘I have a choice!’ was repeated several times. The present research offers evidence for the continued resilience of people with IDD, particularly around sexual self-advocacy. Though people with IDD’s choices and opportunities are often constrained, participants in our study highly valued their ability to make choices.

Limitations

NGT is a useful technique for working with people with IDD, but it is not without limitations. While it did not occur in our study, the possibility that participants could vote at random during the final stage can serve as a reliability threat (Tuffrey-Wijne et al., 2007).

Another limitation of this particular study was the large NGT group size. This study used the NGT in one large group of 35 participants while the typical group is 5-9 people (Moore, 1987; Tuffrey-Wijne et al., 2007). Although the facilitator strove to make sure all voices were being heard, having a large group can potentially impact the depth of discussions that the intimacy of smaller groups may foster. For instance, ensuring that everyone had an opportunity to share meant that there was less time to discuss certain issues that participants mentioned.

There were also areas that could have been more inclusive of the research participants in this study. Although the researchers worked with two people with IDD to plan and organize the forum, participatory research methods such as NGT aim for “*maximum* participation of stakeholders” (Nelson et al., 1998, p. 7). Certainly more people with IDD could have been included throughout the process, including in the data analysis that was done by the research team alone. This limitation serves as an invitation for future research, especially as people with IDD and their allies push for more inclusive studies.

Moreover, group discussion methods (including NGT) are not currently accessible for people with the most severe cognitive impairments. People with IDD with the most severe impairments can have wholly different experiences than people with IDD with less severe cognitive impairments thus potentially generating very different results and priorities (Carlson, 2010). We challenge future research to adapt NGT for the inclusion of people with severe impairments. For example, support people could be carefully included in the process or adaptations can include more physical cues and gestures for those with nonverbal communication.

Conclusion

NGT is a tool that can be used with equal success within practice or research settings. The relatively low cost, short amount of time required, and high yield of data about a concept make it easily transferrable to a variety of contexts. Group homes for people with IDD could consider using NGT to both discuss healthy sexuality with their clients and determine their clients' sexual needs. This is especially pertinent considering the participants' recommendations that they need more access to information and systemic barriers need to be dismantled ([citation removed for blind review], 2014).

NGT's emancipatory potential increases opportunities for people with IDD to produce knowledge about areas that are important to them. People with IDD value research and want to be involved to help make a difference – to have researchers learn about their experiences (McDonald, 2012; McDonald et al., 2013). It is the researcher's responsibility to permeate research with input of those involved; doing so will not only improve research quality but also speak to our ethical obligations (McDonald, 2012). Very often, prominent research design does not consider oppression or liberation and thus does not “often formulate research questions in that vein” (Cocks and Cockram, 1995: 27). It is important for research programs to seek new and creative ways to access information that has previously been hidden or overlooked. While this is not always an easy or linear process, it is an important task. Participatory research methods such as NGT respect oppressed groups' ability to produce knowledge and can push back against the professional researcher's monopoly over research (Cocks and Cockram, 1995).

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