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Quality of Life Research and Methodology:
Developing a Measure for Alaska Native Peoples

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Biographical Information

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Abstract

Quality of life (QOL) is often complicated by global measures that ignore the uniqueness of culture and context. The research is inundated with Western influence and colonized approaches, and indigenous ways of knowing are often overlooked and devalued. Diverse methodologies are a first step in stakeholder collaboration; mixed-methods research and Community Based Participatory Research (CBPR) are a means of capturing the lived realities and worldviews of indigenous populations. These approaches allow for Alaska Native (AN) voice to be present in all aspects of the research process. A culturally relevant and sound measure of QOL for AN peoples must incorporate the voice of the stakeholders and the indigenous knowledge and traditional values that contribute to the beautiful and invaluable cultures of AN peoples.

Introduction

Quality of life (QOL) is complex. Researchers have been debating how to define, measure, and even apply the term within a societal, let alone a cultural, context since its inception into the cannon of wellbeing (Corless, Kennealy, Nicholas, & Nokes, 2001; Felce, 1997; Hunt, 1997; Skevington, Sartorius, & Amir, 2004; Smith, Avis, & Assmann, 1999). Quality of life gained popularity in academia during the end of World War II, when the World Health Organization (WHO) said health is "physical, mental, and social well-being, and not merely the absence of disease and infirmity" (Corless et al., 2001, p. 15). Thus, the WHO began to look at determinants of health that extended beyond the presence or absence a physical illness. During its evolution in American research, QOL has gone from participant appraisal of life experiences to an assessment of need fulfillment (Corless et al., 2001; Prutkin & Feinstein, 2002). However, over time QOL has been subject to a yo-yo type framework and conceptualization that ranges from the inclusion of many domains to the exclusion of almost all domains. QOL is further complicated by the argument that it is often distorted by and entangled in other, separate, constructs such as general health and social status (Corless et al., 2001; Hunt, 1997; Smith et al., 1999).

However, while QOL is a broad term that is individual and group-specific, it is often limited to one or two domains, such as physical and emotional, or spiritual and relational (Prutkin & Feinstein, 2002). Additionally, it has been limited by the disagreement and confusion surrounding methodology, instrumentation, and conceptualization. In other words, the concept of QOL has been adjusted to accommodate the researcher, and the measurement thereof has been constrained within the framework of the researcher, as opposed to the unique cultural and contextual experiences of the stakeholders -- those whose QOL hangs in the balance. Competing forces (e.g., society, specific approaches, categorization) have often complicated and attenuated QOL within, among, and outside of the Western, dominant establishment of the construct. In order to fully understand the scope of QOL research within a cultural context, one must consider not only methodologies and limitations, but also how they interact with indigenous knowledge, Community Based Participatory Research (CBPR), and implications for AN peoples.

QOL has been defined across a broad range of concepts, and has been examined through many methodological lenses. However, the research is sparse on decolonizing approaches to QOL research with indigenous, namely AN, populations (Corless et al., 2001; Hunt, 1997; Lopez, Sharma, Mekiana, & Ctibor, 2012). While systemic injustice and limited access to resources contribute to cultural suppression, cultural strengths such as indigenous knowledge and traditional values contribute to the beautiful and invaluable culture of AN peoples and to their robust QOL in the face of historical and contemporary adversity. In other words, in order to fully understand QOL research as it applies to AN peoples, methodologies, and decolonizing approaches, one must also consider the historical and contemporary aspects and evolution of QOL research through the past and present limitations and through the future advantages of expanding to include indigenous knowledge.

Methodologies

Differing theoretical models, personal perspectives, and content-specific applications have been used to define QOL, with the majority of these measures being aimed at objectively quantifying subjective experiences (Felce & Perry, 1995). QOL is used to track incremental progress of observable phenomenon. For example, it is used to determine whether individuals have improved physical health and/or cognitive function, or to identify individual needs for support or "fundamental changes in services" in a healthcare setting (p. 52). According to Muldoon, Barger, Flory, and Manuck (1998), QOL has been used to measure a person's functional ability to complete normal tasks in general life domains such as their job, their physical health, and their relationships. In contrast, QOL measures have expanded to either include subjective measures or to focus solely on subjective self-reports of a person's perceptions or feelings in differing life domains. This inclusion has not been without considerable confusion and disunion in the field. While some purport this inclusion of subjective measures as progressive and structural, others interpret it as counterproductive (Muldoon et al., 1998; Felce, 1997). In addition, others suggest that subjective and objective measures should be unified, and QOL should be studied with as much inclusion of participant voice as possible (Faircloth, & Tippeconnic, 2004; Gonzalez, & Trickett, 2014; Tammaru, Lember, Polluste, & McKenna, 2007). The division in research methodology and in subsequent applications to individuals in health-related settings has contributed to a general mistrust and disuse of QOL measures from doctors (Muldoon et al., 1997).

One such attempt to mitigate the concerns and to demonstrate the validity and reliability of a QOL measure is the World Health Organization Quality of Life Assessment (WHOQOL), developed in the early 90s (Herman, et al. 1998). This was in response to excessive and narrow measurement of QOL that had poor reliability and did not represent the multifaceted nature of QOL beyond singular dimensions or limited domains. Focus groups, collaboration with experts, and writing panels were utilized across 15 countries during its development. Western scientists were at the helm of ultimate decision-making capacity; as a result, the domains were solidified as follows: physical, psychological, social

relationships, environment, spirituality, and level of independence. The WHOQOL was tested in large metropolitan cities such as Bangkok, Seattle, Paris, Tokyo, Barcelona, etc. Despite this, the cross-cultural application of the WHOQOL has been questioned as to whether it is truly applicable to other cultures and whether the domains are relevant (Muldoon et al., 1998; Skevington et al., 2003). For example, the "level of independence domain" includes "dependence on medicines" (Muldoon et al., 1998). This makes the assumption that the target population has access to medical resources. In the "physical" domain, "pain and discomfort" presumes that an individual or culture will not interpret this in terms of emotional pain. Overall, the WHOQOL has been shown to be valid and reliable in the larger cities that it was tested in; however, little is known about how it fares in indigenous, rural, and/or other cultural settings.

Currently, there is a drive in QOL research to diversify methodology; it is suggested that objective measures broaden to include subjective measures (Klassesn, Creswell, Plano Clark, Clegg Smith, & Meissner, 2012). In other words, interdisciplinary partnerships (e.g., sociology collaborating with biology) and mixed methods are not only gaining traction, but also are becoming a necessary component to validating and advancing QOL. Klassen et al. (2012) suggest QOL researchers are tasked and charged with studying a concept that spans boundaries, disciplines, and methodologies, and "are faced with integrating diverse perspectives, types of evidence, and audiences or stakeholders" (p. 377). Considering different approaches, quantitative methods are based on general principles of science (deductive) and are optimal for measurement of objective, observable phenomenon, while qualitative methods are ideal for measuring subjective, unknown phenomenon. Mixed-methods, a modality of marrying qualitative and quantitative approaches to research, are a way to broach the intricate and multifarious questions raised through QOL research. The researchers point out that mixed methods are not just the existence of the two together in one research project, but the blending of both strengths into one modality. In other words, if one were to use only a quantitative measure, one might gain a strong factual knowledge of a concept, but also might lose the rich and contextual contribution of an organic interaction with the unique voice of the stakeholders.

Felce (1997) posits that QOL research, while predominantly measured globally, should be defined by the lived realities of each individual and each group it aims to understand. He proposes a QOL model—consisting of three essential features or domains—to capture the multidimensional nature of QOL and to guide the unification of objective and subjective methodologies as follows: (1) "life conditions" are the individual or group report of environment, of unique circumstances, and of all the etic aspects of life that make up QOL; (2) "subjective well-being" is the individual or group perception and interpretation of their life and what makes it good, what makes it bad, and the degree to which the two fluctuate and interact; and (3) "personal values and aspirations" are the determinants of how the individuals or groups conceptualize their objective and subject aspects of life (Felce, 1997, p. 127). The researcher has mixed the quantitative and the qualitative within the supposition that both are directly informed by the experiences and voices of the stakeholders. However, it is also recognized that this approach needs to be

taken with much caution, because reported satisfaction of life (i.e., QOL) on Western, global measures has a tendency to be high for ethnically diverse groups and minorities in spite of long-term adverse life conditions (Felce, 1997; Klassen et al., 2012). In other words, when a group of people is consistently oppressed, and a measurement of self-report is used that factors in two or less life domains, these groups of people, having adapted to adversity, will report higher levels of QOL. Hence, Klassen et al. (2012) postulate that methodologies heavily weighted in one method have the potential for missing key determinants of QOL and compromising authenticity.

Limitations and Culture

While the methodological recommendations for QOL research are admirable and inclusive, if not ambitious, they pose many problems and limitations in the face of ethnically diverse populations outside of the dominant culture. Hunt (1997) states that three prime limitations of QOL are measurement, ambiguous application, and confusion around and agreement on the actual term. The researcher goes on to explain that with pressure coming from health companies, insurance companies, and third parties with a stake in the outcome, QOL is a "buzz word" that is popular and not only induces a sense of power in a study, but also to gives it a consumer or client emphasis. However, the measurement and very definition of QOL is more often than not tailored to the answer and the outcome (p. 206). Because of this confusion and ambiguity, many researchers have taken to fractionate and compartmentalize QOL to represent only one domain at a time (e.g., health-related QOL). Arguably, this oversimplifies a complex concept, as even health-related QOL is affected by interpersonal relationships, work, race, status, environment -- and the list goes on. Furthermore, Hunt (1997) argues that for one to narrowly conceive, research, and interpret QOL in a one-size-fits-all way is "to impose an arbitrary set of standards in relation to human experience which may well not apply outside the narrow confines of the...world in which they were devised" (p. 209).

While Hunt (1997) uses health-related QOL as an example of narrowness and imposition not only cross-culturally but also within dominant culture, Smith et al. (1999) states that overall QOL and health-related QOL are two distinct constructs that are often lumped together and, ultimately, convoluted. In this article, they conducted a meta-analysis of QOL studies of chronic illness that contained the following: (1) one score for several domains, (2) global ratings for both constructs, and (3) a correlational matrix between each domain's score and the global ratings. The two constructs, QOL and health status, and three life domains including "mental, physical, and social functioning" were considered across twelve studies that met the aforementioned criteria (p. 447). Plugging the twelve correlational matrices into one matrix, QOL and health status were analyzed separately and together. The researchers found that QOL and health status were different constructs; and social supports, coping styles, and environment, to name a few, were factors that contributed to these constructs. Additionally, they found that people reported mental health as of greater importance than physical functioning in QOL, and physical functioning as of greater importance than mental health in health status. In other words, health-related

QOL is a misnomer, because it is only an objective measure of health status, while QOL is a subjective measure of mental health as it relates to physical health, social functioning, environment, and many other interrelated domains. Smith et al. (1999) says that most QOL studies and measures regard "domains as determinants rather than indicators of QOL" (p. 457). This suggests that inferring QOL for people (i.e., assuming QOL is directly related to the absence of disease) could completely miss the unique perspective, perception, and conceptualization of what QOL means to the stakeholders, particularly if those affected are outside of the *norm* and already disenfranchised and experiencing disparities that span established QOL domains.

The intersection of QOL and culture is complex (Coverdill, López, & Petrie, 2011; Tammaru, Lember, Polluste, & McKenna, 2007; Hughes, 2006). Coverdill et al. (2011) examined the General Social Survey data from 1996-1998 that considered QOL measures. Looking at ethnicity and race, the researchers state that in the United States, Black individuals consistently score lower on QOL measures than White individuals. This is attributed to the *racial tax,* whereby Black people are taxed for being Black through receiving less pay, fewer opportunities, and less access to resources, and through consistently experiencing racism, oppression, disenfranchisement, and marginalization. It should be noted that while ethnically diverse people in America experience more disparities and lower QOL, it is also important to not lump all ethnically diverse people within America into one category. Coverdill et al. (2011) states that "despite its…value, the pan-ethnic approach undoubtedly obfuscates structural and historical factors that differentially impact" QOL (p. 786). In another study, conducted by Tammaru et al. (2007), the researchers examined the Swedish Rheumatoid Arthritis Quality of Life measure (RAQoL) in the geographically and cultural similar country of Estonia. The distinction is important, as the two countries are often seen as one and the same culturally; however, it was found that while the measure was applicable, it missed several features of QOL that are important to Estonians. These included their concerns about their function in daily life roles, the importance of dialoguing with their medical providers, and matters pertaining to money and access to resources. They found that while some populations might appear or report to be similar, cultural differences can be subtle. If these differences are overlooked, it can restrict the bounty and significance of lived realities and diverse worldviews.

Most QOL research strives to include subjectivity along with objectivity (Corless et al., 2001; Felce, 1997; Hunt, 1997; Klassen et al., 2012; Urzua, Miranda-Castillo, Caqueo-Urizar, & Mascayano, 2013). Urzua et al. (2013) asked whether contextual meaning of life is incorporated into cultural QOL measures. The researchers point out that subjectivity, even when exemplified through the voice of the stakeholder, "is not done in an isolated context but rather one framed by the culture and value system in which one lives" (p. 1296). Scratching the surface, it is argued that QOL in a cultural context generally looks at domains such as stress and coping, physical health, mental health, and perceived happiness (to name a few) in individualistic terms, but never has included cultural values, the motivational component driving QOL, in collectivist terms. For example, Urzua et al. (2013) used the Schwartz values paradigm (the notion that values hierarchical and contextual) to

demonstrate that high QOL (subjective wellbeing) is directly associated with individualistic principles such as independence, power, and agency; likewise, low QOL is directly associated with collectivist principles such as customs and conformity. Moreover, universal QOL domains ranging from hedonism to achievement, and power to self-direction have no relevance in cross-cultural, indigenous contexts where collectivism is predominant. The only exception to this distinction is a correlation between individualistic domains and collectivist domains in the presence of colonization. For example, Coverdill et al. (2011) say that Latinos score higher on QOL measures than Black individuals due to their acculturation into White society, and that "the strong tendency for Latinos to identify as white rather than black" could account for the higher, perhaps aspirational scores (p. 800). In other words, a non-white person might score higher on a QOL measure that is grounded in Western culture when they themselves are a product of assimilation and internalized oppression, however, it is extremely important to note that though they score higher, this does not indicate that the measure is appropriate and reflective of cultural values (Smith, 2012).

Indigenous Ways of Knowing

Not only does science often undervalue the indigenous worldview in its attempts to incorporate it, but it regularly does little to assist the indigenous peoples the world over who are struggling to keep their ways of knowing alive and relevant to contemporary generations (Cardinal, 2001). In his personal experience of indigenous ways of knowing, decision-making, and research application, Cardinal (2001) witnessed a board of Elders meet to determine a course of action for a public policy matter. The Elders sat in a circle and each took his/her turn to give their opinion. As each Elder spoke the others quietly and intently listened, and as the voice moved from Elder to Elder, each one tried to understand and summarize what the person before him/her said. At the end of the talking circle time, they all agreed to go home and reconvene the next morning. They all left to their respective tribes and homes to work further on the decision-making process; some practicing ceremony, some entering the sweat lodge, some searching out answers from ancestors in their dreams. When the circle met the next day, each brought with him/her the wisdom and insight gleaned from their traditional practices, even working through visions and dreams. While the incorporation of indigenous methodologies into mainstream research with indigenous peoples is largely neglected, indigenous practices such as dream work and circle work have been used for centuries. As Cardinal (2001) explained, "Indigenous research methods and methodologies are as old as our [indigenous peoples'] ceremonies and our nation" (p. 182). In other words, indigenous approaches to research should be embedded within and infused with indigenous ways of knowing, traditions, worldviews, and real experiences.

Getty (2009) proposes that indigenous lives have been predominantly researched from Western, colonial perspectives. Reviewing the pre-colonial state of the Mi'kmaq peoples of Canada, it is documented they were self-sufficient, having established communication, government, social stratification, and were healthy and thriving people.

The researcher posits that indigenous cultures are innately self-sufficient and should be understood from and within their unique worldviews. Postcolonial life of the Mi'kmaq people, however, is marked by poverty, increased disease, decreased QOL, the presence of other forms of racism, and systemic oppression from colonizers, the state, and churches (Getty, 2009; Smith, 2012). It is noted that the Western colonization and imposed assimilation of indigenous peoples has negatively impacted QOL and contributed to the "soul wound," historical trauma, and "spiritual and emotional injury" that is perpetrated on indigenous peoples from generation to generation (Getty, 2009, p. 6). The fundamental differences in paradigms are evidenced in the Western research attempts to do away with diversity (e.g., the WHOQOL global qualities or the melting-pot approach to conceptualizing cultural differences) and the indigenous push for a respect for diversity through sovereignty. However, Getty (2009) and Smith (2012) suggest that research needs to be not only cognizant of colonialism and its effects, but also be a part of the effort to return sovereignty, to value indigenous ways of knowing, and ultimately, to work toward decolonization.

Faircloth and Tippeconnic (2004) suggest that Native and non-Native researchers consider the following when conducting research incorporating indigenous knowledge:

1. Seek indigenous participation and validate the indigenous voice at all times;

2. Use indigenous methods of approaching research whenever possible and/or applicable;

3. Gather and gain knowledge about the target community and foster rapport and lasting   relationships;

4. Promote reciprocity through striving for bidirectional benefit;

5. Do not conduct research that harms or that does not substantially benefit the target community;

6. Pursue situations and conditions that will give indigenous communities ownership of the data and will shift the balance of power into their favor;

7. Refer to and include indigenous knowledge as much as possible;

8. Research must be culturally sensitive and aimed at decolonizing;

9. The researcher is in the position of service to the target community.

While not exhaustive, Faircloth and Tippeconnic's list of recommendations could not only revolutionize indigenous research in general, but also indigenous QOL research, a means to capturing what truly makes life good for tribal peoples.

Undoubtedly, a cornerstone of research with indigenous peoples is to foster genuine and authentic relationships (Allen, Mohatt, Markstrom, Byers, & Novins, 2012). The relationship with the community influences all aspects of the research. Kinship is an important part of indigenous culture and a strong indicator of the researcher's status in the community and the role in which the community views the researcher. For example, a

researcher can progress from an outsider to a friend to a family member, and the researcher can be greeted in a way that signifies they are outside the community (e.g., the community uses terms that divide them geographically from the researcher) or that they are accepted into the community (e.g., the community uses language that includes them). It is also important that the researcher cultivate this kinship through extensive self-disclosure and personally revealing dialogues. Another facet of shared power and authentic relationships is negotiating time. Many indigenous communities view time as less critical than Western society; the research often has to navigate and respect the decisions to postpone crucial meetings or research due to community events or ongoing collaboration. Kinship plays an important role not only in the beginning of the research process, but also near the end of the research.

Allen et al. (2012) points out that kinship relationships hinge upon dissemination of information. In other words, the way in which the researcher decides to distribute the results of research—whether to the community, to the public, and/or both—can greatly affect the relationships that the researcher and all the following researchers have with the community. Styres (2008) says the researcher has a responsibility to the target indigenous community through maintaining trust, respecting indigenous ways of knowing, making every endeavor mutually beneficial, and honoring the cultural relevance of spiritual principles and the embeddedness of nature in all aspects of life throughout the research process. Furthermore, the connection between researcher and community is a continual, mutual, and relational process that does not end after the study is finished.

Community Based Participatory Research

A paramount modality for incorporating stakeholder voice and working towards decolonizing methodologies is CBPR (Smith, 2012). CBPR is concerned with not only establishing relationships and serving the community, but also with providing the tools for the community to have an active and involved role in most, if not all phases of research (Hoeft et al.,2014; Smith, 2012). Israel, Schulz, Parker, and Becker (1998) examine key components of CBPR and rationales for its use. The researchers postulate that a "recognition of…inequalities…has led to a call for a renewed focus on an ecological approach that recognizes that individuals are imbedded within social, political, and economic systems that shape behaviors and access to resources" (p. 174). In other words, when researchers become conscious of the systemic marginalization and oppression of ethnically diverse people, they have a responsibility to take those factors into consideration and to allow for the voices of those affected to be heard.

The first principle of CBPR is the community is viewed as a separate and distinct identity (Israel et al., 1998). Community identity is expressed in the connections to others, in the shared values and beliefs, in shared symbols, and can include locations, ethnicities, and mutual understandings that separate groups from the dominant, global culture. The second principle is community enhancement. Namely, CBPR takes a strengths-based approach that seeks to empower and bolster the already established assets, connections, and indigenous knowledge. The next principle asserts that the community needs to be

involved in the process of research from beginning to end. When this value is put into practice, there should be shared control and power, and decisions should be made jointly and cooperatively. Community involvement overlaps with the fourth principle that states that CBPR is an integration of traditional knowledge in an active way. In other words, research ought to not only be informed by the stakeholder, but it also ought to inform the needs of the stakeholders: for example, a study that is conceived of and conceptualized from the ground-up in an indigenous community that also influences public policy and ultimately, creates a directly path to the advancement, decolonization, and enfranchisement of the community. Building upon themselves, principles five and six suggest that CBPR "promotes a co-learning and empowering process that attends to social inequalities" and "facilitates reciprocal transfer of knowledge, skills, capacity, and power" (Israel et al., 1998, p. 179).

CBPR is action oriented, creating partnerships and infusing cultural and contextual knowledge into defining the problem, conceptualizations, methods, handling and analysis of data, handling and sharing of results, the intended audience of change, and the protection and implementation of sustainable outcomes. Principle seven is concerned with approaching issues from a positive and ecological perspective. This involves including the strengths of the community (e.g., in QOL this would be domains such as wellbeing and mental health) with the knowledge of the community and their environment (e.g., historical trauma and oppression, colonization, culture). Lastly, principle eight suggests that the knowledge gained from CBPR should be disseminated in a culturally sensitive manner, done with the permission and direction of the stakeholders, and be relevant and valuable to the population of service. Israel et al. (1998) also give a rationale for using CBPR: (1) it increases the contextualization and indigenization of scientific knowledge; (2) it is a cross-cultural, cross-paradigm, cross-disciplinary collaboration and unification of skills and knowledge; (3) it enhances validity and reliability by including the lived realities, worldviews, and experiences of those directly affected; (4) it challenges the tightly-held scientific norms and goes beyond Western methodologies; (5) it champions grounded theory; (6) it has the potential for creating new understandings, collaborations, and mitigating cultural mistrust; and (7) it demonstrates a collectivist worldview and shows a more complete representation of unique, diverse communities. The researchers recognize that CBPR is not the only means by which to conduct research, but they acknowledge that it is a way to do research that is most welcoming of indigenous worldviews and collaborations.

While CBPR is a beneficial means to decolonizing research in indigenous communities, it is also a very complex and nuanced approach (Nicholls, 2009; Rasmus, 2014). Nicholls (2009) discusses the complicated nature of conducting CBPR with indigenous communities that are collectively unique, but comprised of unique individuals. There is an almost dichotomous nature to research that requires the researcher to be open to community-level changes, adjustments, and conceptualizations at any and all phases of research. The researcher proposes the three following critical reflexive tenets to CBPR: self-reflexivity, interpersonal reflectivity, and collective reflexivity. Reflexivity refers to the

bidirectional, causal relationships of action and participation in community-based research. This multilayered approach begins with self-reflexivity: the critical awareness the researcher has of his/her self and their position in history as a colonizer or as a recipient of colonization. This layer is characterized by transparency that transcends personal responsibility and includes personal accountability. For example, it is the duty of the researcher to be honest about the exact nature of their role and the extent of their power before, during, and after CBPR. Also, it is their responsibility to maintain a balance of self-awareness and selfless service to the target community. Interpersonal reflexivity concerns the nature of collaborations and relationships between researcher and stakeholders. This layer is cognizant of the fact that authentic, organic, and genuine relationships are at the heart of CBPR. Lastly, another nuance of CBPR is collective reflexivity: examining the effectiveness of the research, its contributions to policy and/or community change, outcomes and residual influences on the community, and evaluations of who did what and how they did it. In other words, this layer is concerned with construct and face validity: Was the research relevant to the community? Did it contribute to applicable knowledge? And did both the researchers and stakeholders contribute equally? Nicholl's says that these multiple layers of reflexivity are "the ability to see that the hyphen both connects and separates us when we undertake collaborative counter-colonial research" (p. 124).

   Alaska Native perspectives. As mentioned above, AN peoples have been historically and contemporarily researched without collaborative and inclusive methods (Thomas, Rosa, Forcehimes, & Donovan, 2011). CBPR facilitates a tribally based, indigenous approach to research with AN peoples. These methods are culturally relevant and respectful, "responsive to community needs," and are "strengths-based while being mindful of the unbalanced and often harmful research previously conducted" in AN communities (p. 333). Mitigating disparities is a weighted concern in AN CBPR. Warne (2006) states that while research modalities with AN peoples have the promise of promoting cultural strengths and protective factors, the history of unethical research with AN communities has led to a distrust of research and an understandable disinclination to participate. One of the largest barriers to research is the oft practice of researchers going into a community, mining information, and then sharing results with other academics (Thomas, Rosa, Forcehimes, & Donovan, 2011). This paradigm is a direct collaboration between the funding agency and the research institution, with little thought and power given to the stakeholders. Warne (2006) supports the CBPR paradigm for AN communities, where the collaboration is between the funding agency, researchers, community, and where the power is shared. Albeit an impressive endeavor for any Western institution to rescind power, CBPR is set-up to make the process easier to accomplish. When the AN community is mutually and authentically involved, not only does trust and reciprocity become essential, but the benefits expand outside of the community into the future (Norton, & Manson, 1996).

   Considering AN participation and perspectives through a clinical lens, Harper

(2011) describes three primary themes: cultural competence, recognition of the levels of acculturation, and the applicability or inappropriateness of Western approaches. Cultural competence is integral to any context, research or otherwise, where one interacts with AN peoples. Unfortunately, many researchers and clinicians work with American Indian (AI) and AN individuals but have received little to no training on working with and for these populations. Essentially, they are mining information or applying ineffective interventions and coming to conclusions that are ineffective and veiled pronouncements of victim-blaming. For example, it is reported that AN/AI clients are less likely to use mental health service, are more likely to drop out of mental health programs and therapy, and that mental health interventions are least effective within this population (Harper, 2011; Thomas, Rosa, Forcehimes, & Donovan, 2011). While valid, the emphasis is put on the inaction of AN/AI clients, as opposed to the Eurocentric, colonized, and inappropriate methods and application of mental health services being used within the AN/AI community; what is being labeled as underutilization may in fact be a problem with inappropriately chosen interventions. Additionally, Harper (2011) points out that to be ignorant of the historical trauma and oppression in AN/AI populations is to be ignorant of the level of acculturation. It is important to recognize terms that can be positioned in a negative way towards AN/AI peoples: for instance, *identity confusion* can be termed as internalized oppression in response to colonization. However, it is important to also recognize that levels of acculturation have been exclusively unidirectional, presuming that acculturation happens as an indigenous person becomes more Westernized. Alternatively, and perhaps more accurately, acculturation can be bidirectional, where indigenous people move towards traditional ways, indigenous knowledge, and work towards decolonization. AN/AI peoples can also move fluidly into a third identity clarification of biculturalism, where they are comfortable and confident in their indigenous identity and their dominant societal identity. The point is this: There are multiple layers and facets to AN/AI identity, and research based in community collaboration and participation is key to fostering a cross-cultural understanding and giving authority to their unified, yet dynamic, voice.

Quality of life has been measured over different constructs and by different methodological means within AN communities (Goins, John, Hennessy, Denny, & Buchwald, 2006). The distinction between negative and positive reports of AN QOL is entangled in construct issues and objective measures. Goins et al. (2006) examined health-related QOL of AN/AI Elders age 50 and older through a multivariate analysis of the Center for Disease Control Behavioral Risk Factor Surveillance System data. The data, spanning from 1996 to 1998, linked chronic disease with other risk factors and behaviors. It was found that AN/AI participants reported more days of poor health and poorer overall health than the general public. While these reports are limited to the domains of Westernized QOL (e.g., presence of disease is always bad and absence is always good), they could possibly be narrowly identifying disparities and internalized oppression, with no identification of the unique strengths and resources inherent within indigenous cultures.

Culturally grounded methods are integral to collaborative and respectful AN research, and CBPR is designed to bring the indigenous community into the entire research

process in such a way that it revolutionizes the objective and Eurocentric limitations placed on dominant research (Lewis, 2010; Smith, 2012). Mohatt et al., (2004) states that scientific research with AN peoples has predominantly been concerned with Western paradigms, wherein the control and power is held by the researcher and the institution, and the information is gained *about* the participants as opposed to *from* the participants. The researchers (Mohatt et al., 2004) were informed by the Barrow Alcohol Study—a study that mined information on alcohol abuse form AN communities and then egregiously disseminated the results nation-wide (going as far as stating that the community would "go extinct"), without tribal permission or insight, in such a way that was shaming and victim-blaming toward the AN communities (Foulks, 1989, p. 3). With the ramifications of this in mind, the researchers set out to redefine the substance abuse disparities within AN communities in terms of sobriety, protective factors, and AN strengths through the People Awakening Project (Mohatt et al., 2004). However, the People Awakening Project, as this endeavor came to be called, was a continual process on the part of the researchers to consciously diminish their Eurocentric views and diminish the research-participant power dynamics. There was also an acute awareness of the colonizer-colonized power dynamic at play. The researchers were continually challenged to bring their views into an acceptance of indigenous ways of knowing, to share roles and responsibilities, and to be present and truly listen to the AN people. The People Awakening Project was a first step in mitigating disparities through research with AN Peoples.

Another important example of CBPR with AN communities was the work of Lopez, Sharma, Mekiana, and Ctibor (2012) at the University of Alaska Fairbanks (UAF). Aimed at addressing low retention rates for AN students, a culturally grounded, two phase CBPR mixed method study that conceptualized, defined, and established QOL domains for students, asked the question, "What makes life good?" (Lopez et al., 2012; Sharma et al., 2013). The first phase was dedicated to building a lasting trust with the AN student community at UAF. The study was a collaborative effort between the researchers, AN students, Rural Student Services (RSS) at UAF, and the Center for Alaska Native Health Research (CANHR), with the goal of developing a culturally grounded and relevant QOL measure to help inform systemic efforts to increase AN graduation rates and understand contextual AN QOL. This measure was also concerned with "facilitating co-learning, capacity building, and equity among all partners" (p. 2).

During this first formative phase, workshops were instituted in order to discuss the research with the stakeholders and to invite them to be co-collaborators in all aspects of the process, including development, data collection, analysis, and information sharing (Lopez et al., 2012; Sharma et al., 2013). From the trust-building workshops and through continual and collaborative meetings there developed a total of six focus groups between AN students, RSS, CANHR, and the researchers (Lopez et al., 2012). The focus groups consisted of a women-only group, a men-only group, a non-traditional student (i.e., not directly from high school) group, and three open-gender groups. Each focus group began with a word association task. Participants were asked to write down words or phrases about "life," "quality," and "quality of life" (Sharma et al., 2013, p. 3). Participants were then

asked to write down as many things as they could think of that were associated with what "makes life good," and the responses were read aloud and placed on a board where everyone decide how they fit together (p. 4). Trust-building topics explored after focus groups were the use of AN traditions by researchers to try and be "more Native," the issues with walking in two worlds, barriers and strengths associated with QOL, and hopes and fears of information dissemination (Lopez et al., 2012, p. 4). Additionally, after each focus group, the co-collaborators engaged in analysis of the 35 QOL domains that were eventually reduced to eight domains.

The eight domains and examples are as follows:

1. The culture and traditions domain contains activities such as practicing traditional ceremonies or participating subsistence hunting;

2. The spirituality domain includes relationships with Creator and attending religious services;

3. The values domain is the intersection and symbiosis of Western and traditional ways of thinking or behaving;

4. The relationships domain includes concepts such as connectedness or community;

5. The learning domain incorporates aspects of collegiate life like academic connections and getting good grades;

6. The basic needs domain includes elements of physical and emotional survival;

7. The leisure domain includes features of life such as stress and coping and having fun;

8. The health domain includes facets of life such as exercise and safe sex practices.

After the domains were identified and defined, the next part of the study consisted of pilot testing the developed measure of AN student QOL (Sharma et al., 2013). One hundred and eleven AN students were tested, and the measure was further validated to the population and the questions were reduced from over 100 to considerably less than 100. Overall, the study not only exemplified the power of CBPR with AN peoples and highlighted the importance of building trust with indigenous communities and even between campus communities such as RSS and CANHR, but it also laid the foundation for stakeholder-created QOL domains.

Conclusion

Quality of life is an ambiguous yet ever-present concept. It is still in its formative years, as science struggles to define it, distinguish it from other constructs, and to apply it within diverse cultures (Corless et al., 2001; Hunt, 1997; Skevington, 2004). While it has been measured and tested cross-culturally, its limitations for ethnically diverse and minority populations abound (Corless et al., Smith, 2012). These constraints are currently being mitigated by the call for mixed methods and CBPR, research that ventures to

decolonize oppressed peoples through indigenized methodologies and raising critical consciousness (Smith, 2012). Respecting and including indigenous knowledge and paradigms, adopting critically reflexive approaches, and striving for research that is culturally grounded all play a part in empowering indigenous peoples (Cardinal, 2001; Faircloth & Tippeconnic, 2004; Lewis, 2010). AN peoples have experienced historical oppression and trauma, microaggressions, and internalized oppression, and have historically been exploited and abandoned by Western, Eurocentric research (Harper, 2011; Mohatt et al., 2004; Thomas et al., 2011). In order to reestablish trust and strong avenues of communication and collaboration that promote sovereignty and value diversity, it is imperative that current and future research with AN peoples share power, appreciate contextualized realities, esteem unique worldviews, and honor AN voices. Furthermore, an integral and salient first step in healing is acknowledging the inherent strengths and abilities of AN cultures as they relate to QOL—rather, all the things that make life good.

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