From respect to rights to entitlement, blocked aspirations and suicidal behavior

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ABSTRACT

Dr. Bill Richards was a noted psychiatrist who worked with Alaska Native people for many years. This paper was taken from notes he used for a slide presentation at a conference. In it, he discussed the possible relationship between rapid social change and the increasing rates of suicide among northern people. He summarized the limitations in the existing suicide data, including its essentially descriptive nature, the short time periods of study, small numbers of observations and lack of complete health service use information which could help anticipate a suicidal event. Richards noted the importance of suicide as an indicator condition that could be used to link social survey and health information data bases.

He closed his paper with a discussion of the transition from an era of "rights" to one of "entitlements," and described his observations of growing overt anger and hostile dependency upon government programs. Last, Richards related his concerns over the collection of health service use and epidemiological data associated with a suicidal event.

Keywords: Suicide, health status measurement, behavioral risk, Alaska and Russian Indigenous communities.

This paper presents a condensed summary of material addressed in "Working Papers" of the "Social Transition in the North" project (1).

A problem that has been of interest to our project is that of suicidal behavior, since rates in a number of Alaska and Russian communities appear to be high and increasing, and social transition seems likely as a contributing factor. Populations undergoing rapid social change can show increased vulnerability to disease. As John Cassell and others have suggested (2-7), in these situations "the actor is not receiving adequate evidence (feedback) that his actions are leading to anticipated consequences... It is probable that when individuals are unfamiliar with the cues and expectations of the society in which they live... they should be more susceptible to disease than those for whom the situation is familiar." Once populations adapt to new circumstances, their health prospects improve, but this may take a generation or more to occur. Family solidarity can be an important factor in buffering against the more negative aspects of change (see, for example, studies of communities such as Roseto, Pennsylvania) (11). There also appear to be aspects of personality that can assist in coping with change and protecting an individual against disease—what Kobasa has termed "hardiness" (8), Antonovsky a "sense of coherence" (9), and Rutter "resilience" (10), as well as individual risk factors that can interact with the social and family factors to render a given individual more or less vulnerable.

There are considerable challenges, however, when one tries to move from relatively general statements about populations in transition, buffering, resiliency, and the like, to detailed descriptions...
of how "community-level" characteristics, social structure, and change might impact on or interact with family and individual health behaviors or a particular type of problem such as suicides in specific in Alaskan and Russian communities. When one starts with questions like "what evidence would convince me about these types of interactions?" or "how would I go about measuring the suicide problem sufficiently so I could compare very different types of communities?" one soon arrives at the opinion that very limited relevant data is already assembled on either the Alaskan or the Russian side.

Much of the available health information is about individuals—problem-oriented medical records for individual patients, birth and death certificates for individuals, narrative self-reports, etc. When one tries to correlate this type of information with data from another level—for example, family data or aggregate data about community characteristics, one is left with something of a woozy feeling, as if one were looking at a poorly done "collage" where different kinds of things were all thrown together without much integration.

The information that is available with respect to suicidal behavior in the particular populations we are studying, moreover, has been largely descriptive, with some fairly major gaps in what has been described, and no use of case-control or prospective cohort types of analytic methodologies. To list just a few of the problems with what has been done:

1. Most of the past studies have involved relatively small numbers of observations, made over fairly short time periods. They have focused mainly on individuals, with case reports or small case series, rather than describing the extended family or community interactions. Changes over longer time spans in suicidal behavior patterns have not been well described.
2. There has been a tendency to lump together people who may be at very different developmental stages and consider them as all having the same type of problem, which may not be the case. For example, those aged 15 to 24 may be considered as a homogenous group, while in fact a 15 year-old teenager may have a very different set of risk factors and coping abilities from a young adult of 24.
3. There has been a tendency to describe completed suicides, since death certificate data has been easier to come by than information about suicide attempts.
4. There has been a tendency to describe suicidal problems without describing the interactions with the health system in much detail. This is critical information from a program standpoint, since activities of first responders, management of the patients when admitted to a hospital or other facility, and the type of after-care and follow-up, can be major influences in what the results of the suicidal behavior are.
5. Cultural aspects and meanings to suicidal behavior, described from the point of view of the local people, rather than from the perspective of "outsiders," are usually not available in more than a very general way.

Given these major types of problems, a preliminary task of describing suicidal behavior in at least a few communities in considerable detail seems like a good step, before trying to compare all the Russian and Alaskan communities in our study. Otherwise, any comparisons would have to be limited to very broad brush types of statements. We feel the data is more comprehensive in certain Alaskan communities, because of a sophisticated computerized health information system that has been developed allowing for tracking of suicide attempters, and linking of health data with other types of social data. The slides that follow give some summary information about this system and the preliminary "scouting of the terrain" that is being done to try to understand suicidal behavior better.

Decisions as to what is most relevant to compare between the Alaskan and the Russian communities should be improved by these attempts to first get additional depth information about suicidal behavior in a selected smaller group of communities.

The Alaska Area Native Health Service component of the US Indian Health Service data system basically tracks all the health encounters of 180,000 eligible beneficiaries, including virtually all 87,000 Alaska Natives plus a large number of other people
who are eligible for care because they are on the staff, are dependents of other people who qualify for care, etc. The sorting and filtering capabilities of the system allow one to pull out information on whole villages, or other groups of interest, link data to vital statistics and other computerized information including cost of care data, provider profiles, etc., in ways that were not possible in the former hand-written record system.

There is potential for linking social survey and other types of information being gathered in the Social Transition in the North project (self-report data, survey responses, focus group data, family tree and transition descriptions, social and economic data, ethnographic data, etc.) with the types of information available in the medical information system. It is also possible to follow people over time, basically with the potential to create specialized "registries" and track cohorts with large numbers of people over time, as well as the ability to pull up computer summaries giving detailed information about individuals’ health behavior over time.

Suicidal behavior is being used as one "indicator condition" to explore what can be done by linking the social survey and the health information databases. Similar methodologies, once worked out for suicide, could be applied to a variety of other health problems, both in Alaska, and in other locations where a similar health information system is in use. For certain kinds of problems, such as questions about well-defined biomedical problems, with clear-cut diagnostic criteria, lab tests or other biological indicators that can be used to cross-check the diagnoses, the medical information system can be very useful in its current form. For problems such as suicidal behavior, where diagnostic criteria are not as clear-cut, information documented in the medical charts is often incomplete, and there can be a subjective element as to the meaning of certain symptoms, primary data such as the types of information being gathered directly from families by the Social Transition project that can be correlated with the health information can provide a much richer description and understanding.

Here is a brief summary of the scope of suicidal behavior among Alaska Natives, with concentration on the Kotzebue region where we feel we have the best case-finding and data reporting. Special emphasis is given to self-inflicted injuries involving firearms, which have more likelihood of fatality and also can be extremely costly from a public health standpoint when severe attempts fail (costs of medical air evacuation for surgery, craniotomy and intensive care costs, longer term disability costs, etc.). A focus on younger people who are still relatively early in their "suicidal careers" is being used, with an eye to developing early intervention programs. Besides a focus on community prevention and education, there is a description of what the care system responses are (first responders, hospital and facility staff, follow-up and after-care program staff), in enough detail so that improvements in services and training will be possible.

Special efforts are being made to describe the types of shift as moving from "rights" to "entitlement and blocked aspirations." Information about economic and social changes that have taken place in these communities over time is being assembled. This includes information on population shifts over time, individuals’ description of "transition time-lines" and key developments they feel have impacted on their lives and health behavior, information from our surveys about extent of retention of Native language use, subsistence activities versus cash economy occupations, aspirations for the future, extent of mixed marriages, time spent living in cities versus in villages, and legal changes (land claims rights, right to local schooling, right of self-determination, etc.) are being correlated with changing patterns of health behavior. Associated with the civil rights movement in the late 1960s and early 1970s, there were changes in the mental health laws affecting suicidal patients, including more "patients’ rights" protections, restrictions on involuntary commitments to those suicidal patients who were imminently dangerous with the former concept that people could be "gravely disabled" seldom used as a grounds for commitment, and encouragement to "de-institution-
alize" suicidal patients as much as possible. Legally the concept of "gravely disabled" was seen as a form of paternalism that should be restricted, whose "rights" had been inappropriately taken from them in the past.

A number of local service providers feel that there have been qualitative changes over the past 10-20 years, so that we are moving from an era of "rights" to one of "entitlement." What is meant by this is that, at the community level, there is more overt anger and racial tension, and at the same time a sense of hostile dependency on government programs. There are demands for "local control" and "empowerment," but limited numbers of local people with the types of highly specialized skills and training that are needed to run a modern health care system. At the family and individual level, there appear to clinicians to be an increasing number of people who have grown up in alcoholic families with inconsistent child-rearing. In some cases, the children have fetal alcohol effects or other organic problems resulting from high risk pregnancies, childhood meningitis, gasoline sniffing, or other substance abuse at an early age, making it difficult for them to learn and often emotionally labile. In a number of cases, there are histories of child abuse and child sexual abuse. Children raised under these conditions may have relatively poor coping skills, and as they become young adults, develop a pattern of being angry, impulsive, easily frustrated, with limited abilities to set goals, follow-through on plans, or consider needs of a larger group instead of just their own narrowly conceived self-interest. Under these conditions, the idea of "rights" among autonomous equals starts to break down, so that some other term such as "entitlement" seems indicated since special handling and protection of people who have limited competency is needed. The need to have better understanding of family, social, and cultural support systems in dealing with this emerging very difficult type of suicidal behavior is clear.

An example would be a suicide attempter who had grown up in an alcoholic family, where he was the middle of seven children. A younger sister was mentally retarded, probably from fetal alcohol syndrome, and the next oldest sister was marginally retarded as well, probably from fetal alcohol effects. The boy’s father had died when he was young from an alcohol-related accident. The boy had been sodomized repeatedly by an older brother while growing up. He describes himself now, at age 28, as feeling like a "life-time of failure," who was "born sick." He has trouble concentrating and appears unable to maintain direction in occupational and subsistence activities. He appears to have severe difficulty in areas of independent living skills, impulse control, and judgment, and has recently been involved himself in sexually abusing a young child. He abuses alcohol, and does not comply well with treatment programs. The clinicians conclude that, "lacking supervision and external direction, he is socially maladaptive." He creates situations, in a somewhat manipulative way, where he needs to be helped, getting quite angry at times, or suicidal, with many expectations that non-Native agency workers or his family members look after his basic needs, and provide him financial and other help. At times he presents his problems as spiritual ones, with talk about being possessed by devils, religious persecution, etc., and at times has been unsuccessfully treated by the psychiatric system. He refuses to comply with medical treatment, and has a gun which at times he threatens to shoot himself or others with. One gets a feeling from him best described as "impotent rage."

Information about boys like this, as well as the community aspects to entitlement and dependency, is being assembled through a combination of case vignettes, chart reviews, focus groups, and institutional interviews. For people in our study sample, a wealth of social information can be linked to the clinical information to provide a very rich description of family and social dimensions to suicidal behavior which has not been possible in the past. To better track and provide services to these types of disabled patients, a surveillance system and "case-control" studies are being developed.
CONCLUSIONS
There are two main points that might be discussed about the types of information-gathering described above, with respect to the theme of this conference which is human rights.

1. Human rights and the development process: There appears to have been a "development process" at work, in both the Alaskan and Russian communities, where outside groups have come in and made major changes in the economic and social structures of the local indigenous peoples. In Alaska, there is a long history of attempts to extract natural resources—ranging from furs to gold to timber and more recently oil. In Russia, the Far North and Far Eastern areas are known to have extensive natural resources likely to be rapidly developed over the coming few years, with extreme pressures to move quickly because of the current economic problems in the country. Besides concerns about environmental pollution connected with this development process, there also needs to be improved understanding of the "human pollution" that can result if development is carried out in a "boom or bust" type of fashion with little attention to the rights and longer term best interests of the local inhabitants. The health systems in both countries have to deal with "social fall-out"—including at least a portion of the community disintegration, family breakdown, and problems such as alcoholism, suicidal behavior, and other "transition" problems—when the development process is rapid and insensitive. Better understanding of ways the development process could be carried out in a less "polluting" way could be very helpful in preventing many types of problems where the surface symptoms are currently getting labeled "human rights" problems.

2. Human rights and "big brother" data systems: The kinds of information available through health information data systems such as are described here make many people leery. There seems to be tremendous potential for invasion of privacy, loss of confidentiality, or other misuse of such a system. On the other hand, because of the pressures to contain and manage health care costs, the system described here is part of a trend that is likely to continue. Health maintenance organizations and similar groups are increasingly having to care for a population of people, and have a fixed amount of money to work with. The Indian Health Service is therefore not the only group developing sophisticated computerized health information systems that will allow for tracking of individuals, targeted health conditions (especially "expensive" ones), practice patterns of individual health practitioners, etc. For studies of social, community, and population-based aspects to health, the types of analysis outlined here are likely to be just the "tip of the iceberg." There are needs of larger organizations and groups who are under pressure to be very efficient in getting the most from the limited health dollars they have to work with, to be balanced against rights of individuals for privacy. Social scientists may have some new opportunities presented by the emerging health information technology, but also will have many ethical issues to ponder.

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