

Adaptive Daily Living Skills in Northern Ontario First Nations Communities: Results from a Diary Study

Abstract

This study aimed to gain a better understanding of the adaptive daily living skills (ADLS) of people living in remote northern Ontario First Nations communities through the use of a diary study. Eight individuals living in First Nations communities were asked to describe their activities for one week by writing them in a diary. The most commonly reported activities were child/eldercare, travel, socializing, and use of electronic media. Results also highlighted some ADLS unique to these communities not generally measured by standardized questionnaires including fishing, hunting, and attending community feasts. Of note was what services were not available in these communities. This included group homes, respite services, day programs, and other supports for individuals with intellectual disability (ID) found in larger urban centres. This highlights the importance of family support for individuals with ID and dependence on community members for assistance. Results will be used to create a new standardized questionnaire to more validly and effectively measure ADLS in northern Ontario First Nations communities.

Melissa is an adult with an intellectual disability (ID) who lives with her grandmother in a small First Nations community in northern Ontario. There are no roads into her community in the summer time, but Melissa has flown on an airplane to other towns many times for medical appointments. Melissa likes to help with community feasts, go fishing with her cousins, and buy things on the local TV auction. Her favourite food is moose meat stew which she helps her grandmother to make. Melissa also helps her grandmother with chores around the house like carrying firewood inside and going to the Northern store to buy supplies. Melissa's grandmother speaks Oji-Cree a First Nations dialect at home but at school Melissa was taught in English. Now, she speaks a little of both languages.

Living in a remote community in northern Ontario Melissa has a very different routine than her peers in the city and this can make it quite challenging to measure her functional abilities, or her adaptive daily living skills (ADLS). ADLS can be defined as the functional skills needed for everyday life (Harrison & Oakland, 2003). ADLS include practical activities such as self-care and domestic skills; conceptual activities such reading, writing, and handling money; and social activities such as interpersonal and recreational skills. Although there are undoubtedly many ADLS that Melissa would have in common with people living in large cities, cultural expectations and environmental conditions will shape and influence what type of skills are valued and reinforced, and therefore learned, by Melissa in her particular context.

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The ability to provide an accurate assessment of ADLS is important for individuals with ID and their families for a number of reasons. First, an accurate assessment of ADLS is important for developing training and treatment programs. If information is inaccurate or invalid it may lead to interventions that are inappropriate or not helpful for the individual and their family. Secondly, the ability to report on and measure ADLS is an important step in accessing funding resources for individuals with disabilities. Many government subsidies require that an individual with a disability receive an assessment of their support needs and abilities in order to establish eligibility prior to receiving funding and resources. It is therefore critical that accurate tools be available to complete these assessments and allow individuals to receive support if appropriate. Given the limited financial resources in some First Nations communities this is an important priority.

Assessment of ADLS in adults with ID is generally accomplished using one of a number of popular standardized questionnaires. These questionnaires are typically completed by a care-provider who knows the individual with ID well. The questionnaires yield standardized scores comparing people of the same age on their ability to perform a broad range of tasks. Some of the most popular standardized tools for assessing ADLS include the Vineland Adaptive Behavior Scales-II (Sparrow, Cicchetti, & Balla, 2006) and the Adaptive Behavior Assessment System-II (Harrison & Oakland, 2003).

At present, a major barrier to effective assessment of ADLS for individuals in remote First Nations communities is that standardized questionnaires are often geared toward individuals living in large urban areas. Many of the items on these instruments are of questionable validity, or even entirely irrelevant, for individuals living in smaller towns. For First Nations communities the problem is even more pronounced. For example, using public transit, going to the bank to withdraw money, or visiting a movie theatre are activities that would generally not take place in these communities and therefore these skills would not be important to learn. Questions about these types of activities and many others specific to larger communities are currently part of both the Vineland Adaptive Behavior Scales-II and the Adaptive Behavior Assessment

System-II. In addition, many expectations and social conventions are different in First Nations cultures. One simple example is that cultural expectations regarding "looking at others' faces when talking," and "smiling and nodding" to encourage others in communication are different for First Nations individuals, making questions such as these from the Communication subscale of the Adaptive Behavior Assessment System invalid for this group.

As well as containing irrelevant items, a broad range of culturally appropriate ADLS that an individual may learn while living in a First Nations community are not captured by existing standardized questionnaires. For example, fishing, hunting, and engaging in traditional arts and crafts are important activities in many communities. These skills are not measured by current instruments. Taking part in large community events such as feasts is also an important part of life in the north, and activities such as this are also not included in current ADLS measures.

Previous researchers who have focused on assessing individuals in First Nations communities have also commented on the "cultural inappropriateness" of many existing instruments (e.g., More, 2002). Authors who have attempted to measure ADLS in older adults from First Nations communities have reported difficulties with existing instruments and biases in their data as a result (Moss, Schell & Turner Goins, 2006). In the related area of intellectual assessment, much research has reported variations in assessment scores between First Nations children and Caucasian children and often it is noted that one possible reason for this may be cultural and environmental differences (e.g., Dolan, 1999; Madak, 1990; Mushquash & Bova, 2007). The importance of having culturally appropriate instruments available to accurately assess individuals has been discussed by a wide variety of experts and agencies, including a United Nations task force (IASC, 2007).

The purpose of the present study was to gain a better understand of the daily activities of people living in remote First Nations communities through a diary study. A diary study was chosen because it is a relatively unobtrusive method of gathering information and it allows respondents to report information in their own way,

highlighting what they feel is most important rather than having this perspective imposed by the researchers. In their review of how diaries have been used in psychological research Bolger, Davis and Rafaeli (2002) noted that diary studies are useful for capturing the context of an experience and reducing the effect of retrospective error, omission, or bias. This makes a diary study ideal for gathering accurate and detailed information about daily life in these communities. Of special interest in this research was respondents' reports of unique or "novel" activities which do not typically occur in larger urban areas. This study was the first step in a larger program of research aimed at improving and adapting existing Developmental services for First Nations communities and creating a new tool for assessing ADLS in adults with ID living in these communities.

Materials and Methods

Participants

This study was reviewed and approved by the Research Ethics Board of an Ontario provincial government transfer agency. Individuals associated with a clinical videoconferencing program in Ontario, and known by videoconferencing program staff to be fluent enough in English to complete a diary, were approached and asked to take part in the study. A total of eight individuals (five women and three men) from five different communities agreed to take part. As the goal of this research was to understand the types of activities that occur in the community, rather than the individual's skill at completing them, both individuals with ID and those without ID were welcomed to take part. One participant was diagnosed with ID and seven were family members of individuals with ID. Each of the eight participants resided in a different home, and to our knowledge, they were not related to one another. Age in years of participants was as follow: 21, 31, 31, 35, 46, 48, 53. One participant's age was unknown.

To be included in the study, individuals were required to be residing in a First Nations community in northwestern Ontario and attempts were made to approach participants in a variety of different communities. Of the five communities represented in the study, three were "fly-

in" only and had no road access in the summer months. Two were accessible by road all year long. The communities had populations ranging from 253 to 1843 according to Statistics Canada census data (Government of Canada, 2006). Two communities were primarily Ojibwe speaking and three were primarily Oji-Cree speaking.

The investigators in this study (VT, DB, CS) were all clinicians involved in a videoconferencing program that delivers specialized services to adults with ID living in northwestern Ontario communities. The program is a partnership between a variety of clinical, community, and healthcare agencies housed in both northern and southern Ontario. Program clinicians meet with individuals on videoconferencing throughout the year and clinicians from southern Ontario travel to various towns and communities in northern Ontario to meet individuals and their families in person twice per year. VT is a clinical psychologist who has worked for the past 12 years in the field of Developmental Services. DB has worked for 30 years in the Developmental Services field as a front-line support worker, Behaviour Therapist, and presently as the Hub Coordinator for the videoconferencing program. CS has worked in Developmental Services for 21 years as a front-line staff, residential supervisor, and currently as Community Outreach Supervisor for a First Nations health service agency.

Procedures

Diary information was collected using an interval-contingent design (Bolger, Davis, & Rafaeli, 2002). This method asks participants to complete their diary entries at specified intervals, in this case daily, over a period of seven days. The study was explained to each participant and consent obtained. Each participant was sent a 7"x9" soft cover, lined paper notebook through the mail. Simple written instructions describing how to complete the diary and examples of possible entries for a day were attached to the first page of each diary. Participants were asked to write down all the things they do in a day but were informed that they could decide not to include some activities if they felt the activities were "private." After completing the diaries for seven consecutive days, the participants were asked to mail them back to the investigators. An honourarium of \$50.00 was offered to thank participants for their time and effort.

Results

Analyses

Information from the diaries was interpreted using Content Analysis. This involves identifying coherent and important themes and patterns in the data, developing typologies or categories, and reviewing the validity of these

categories (Patton, 1987). Initially, all diaries were read and reviewed by the primary investigator (VT) to extract a list of unique or novel activities. Novel activities were defined as any activity that would not be captured by existing measures of ADLS. This included both culturally specific and location specific activities. Novel activities were grouped based on similarity and are presented in Table 1. Among the

Table 1. Novel Daily Activities Reported in First Nations Communities

Household Management:

Order firewood, chop firewood, start and monitor fire in the stove
 Manage the household during power outages
 Cook moose meat stew, cook bannock
 Clean fish, cook fish on the fire
 Take garbage to the dump

Community Interaction:

Help prepare for/attend a Community Feast
 Help prepare for/attend a Community Memorial
 Help with community clean-up day
 Arrange and manage credit at the Northern store
 Travel to the airport, pick up guests
 Provide care to elders
 Make arrangements to travel out of town for healthcare (flight, hotel etc)
 Go to the Band office to manage administrative matters

Media Use:

Take part in TV auctions
 Play radio Bingo, buy Bingo cards
 Go for videoconferencing/telehealth appointments at nursing station
 Buy dinners from the community TV channel

Leisure:

Walk around town
 Go fishing, buy minnows
 Drive all-terrain vehicle (ATV), snowmobile, boat, dirt bike
 Go for a drive in the bush
 Chase a partridge in the woods

Table 2. Activity Categories and Descriptions

<i>Child/Elder Care</i> : medical care for child or elder; housekeeping, cooking for child or elder; personal care for child or elder such as help with dressing, shopping, get ready for school
<i>Travel</i> : drive a car, bike, boat, ATV; go on a plane; packing for travel; stay at hotel
<i>Socializing</i> : visit family, friends; telephone calls to family or friends
<i>Media</i> : watch TV; use the computer; listen to radio or music
<i>Domestic</i> : household chores such as wash dishes, clean rooms, laundry, take out garbage, make bed
<i>Food Preparation</i> : prepare food for self; buy take-out food
<i>Shopping</i> : shop in town or at Northern store; buy things by auction on TV or radio
<i>Exercise</i> : walk, ride bicycle, jog, weight training, organized sports
<i>Community Event</i> : Spring cleaning, feasts, memorials, birthdays, new baby parties, funerals, sports events as a spectator
<i>Reading</i> : books, magazines, newsletters/papers; studying for school or courses
<i>Hunting/Fishing/Gathering</i> : hunt with guns or traps; fish in a boat or off land; gather berries
<i>Maintenance</i> : fix or repair the home; repairs to a car or other vehicle; bring in wood, chopping wood; sewing or repair clothing

novel activities reported, community-based or large group interactions were most common. Memorials to commemorate the anniversary of a community member's death, community feasts, dances, and celebrations were frequently discussed in the diaries. Also of note from the list of novel activities was the operation of wood stoves which are used to heat homes in some communities.

Next, attempts were made to group the remaining activities listed in the diaries based on similarity in order to develop "activity categories." This was accomplished as follows: (1) fourteen preliminary categories were created using the Adaptive Behavior Assessment System-II and the Vineland Adaptive Behavior Scales-II as a guide; (2) four complete diaries were reviewed and coded by the primary investigator using this preliminary category system; (3) the initial categories were evaluated and then modified based on the extent to which they included most data and minimized overlap; (4) two categories were dropped due to low frequency of occurrence leaving twelve categories. These twelve categories were then used to code activities from all eight diaries. The category names and definitions are reported in Table 2.

Reliability of coding and categories was established by having a second investigator (DB), blind to the initial results, code all eight diaries using the same twelve categories. Intraclass correlations were used to establish level of inter-rater agreement. Results found reliability coefficients within acceptable levels for most categories (see Table 3) with the exception of "Maintenance" which was negatively correlated at $-.72$. This indicates that the two raters frequently disagreed on when this category occurred within the diaries. For this reason, "Maintenance" was dropped from further analyses.

In order to establish which activity categories were most often reported among participants, the number of times each category occurred was calculated as a percentage of total activities coded. For example, the activity category "Media" was counted 85 times across all eight diaries. The total number of activities coded for all eight diaries was 621. "Media" therefore accounted for 14% of all activities reported (85 divided by 621). Percentage results for all categories are presented in Table 3. The most frequently reported activities for participants included child/elder care, food preparation, social activities, and media activities.

Table 3. Reliability of Coding and Categories: Intraclass Correlation Coefficients and Percentage of Total for Each Activity Category

<i>Activity</i>	<i>Correlation</i>	<i>% of Total Activities</i>
Child/Elder Care	.94	18
Travel	.63	17
Socializing	.96	14
Media	.99	14
Domestic	.96	12
Food Preparation	.92	8
Shopping	.96	6
Exercise	.99	4
Community Event	.82	3
Reading	.95	2
Hunting/Fishing	.82	2

Discussion

This study was aimed at gaining a better understanding of the daily activities of people living in northern Ontario First Nations communities through the use of a diary study. The project constitutes the first step in the development of a new measure of ADLS for adults with ID living in these communities. Results highlighted a group of unique or novel activities that occurred, and a coding system was developed to group reported activities into categories. The most commonly reported activity categories were child/eldercare, travel, socializing, and the use of various forms of electronic media such as TV, internet, and radio.

An overall theme that became apparent through review of these diaries was the importance of social and interpersonal skills within First Nations communities. Frequency analysis found that social interaction was the third most often reported activity (14%) for respondents. As well, many of the novel or unique activities reported involved “community interaction” which often entailed large groups of people gathering for food, ceremony, or entertainment. In addition, respondents frequently described social events preceding or following a variety of other activities. Visiting extended family members and working together on some activity occurred daily for most individuals.

When the skills needed to be involved in this type of social activity are considered it becomes apparent that the ability to maintain good relationships with family members, work together, and behave appropriately in large groups is very important in this culture. From a broader perspective, this likely also speaks to a world-view where interdependence is the goal for adult individuals rather than independence (Gerlach, 2008). In his discussion of “Indigenous” beliefs and culture, Wilson (2008) describes the concept of “relationality” as being “at the heart” of what it means to be Indigenous. This involves seeing the world as made up of the interconnections and interrelationships that bind people together. He notes that this belief is more than just seeing relationships as important—it is seeing them as the very definition of an Indigenous individual. This view could have important implications for adults with ID when developing programs and services. Helping to keep interpersonal relationships intact and healthy may be one of the most important goals for service providers when working with individuals with ID from First Nations communities.

Individuals in this study also reported engaging in a great deal of child/eldercare. It was, in fact, the most commonly reported activity at 18%. This again speaks to the importance of the interrelationships and interconnections present in First Nations communities. Although both

males and females were involved in providing personal support to children and older adults, the females in this study did appear to engage in childcare more frequently.

Under the general heading of health and safety skills, it is interesting to note that the use of wood stoves to heat homes was reported several times in this study. In order to operate a wood stove it is necessary to obtain an appropriate amount of wood, use an axe to chop it, and monitor an open fire for safety. This presumably leads to the need for a variety of daily living skills associated with these activities not generally developed in larger urban areas. Although not directly mentioned in the diaries, other health and safety issues associated with life in rural areas such as boating and water safety; understanding when it is safe to travel across frozen lakes; safety in harsh weather; and the use of hunting and fishing tools, are likely quite important in these communities. Health Canada has reported high rates of unintentional death and injury among First Nations communities due to a variety of factors including relative isolation, lack of emergency services, and the physical conditions of housing and other facilities (Health Canada, 2001).

Also of note in this study is what was not reported to occur. People did not go to banks, restaurants, department stores, or theatres. They did not go to a local swimming pool for exercise, go bowling, or work out at the local gym. The reason for this of course is that the facilities for these activities don't exist in most northern communities and this likely leads people in the communities to engage in different types of things in their spare time. As well as fewer commercial resources, there are also fewer social services available when compared to urban centres. For example, there are no group homes or supported residences for individuals with disabilities, and frequently no childcare or senior's centres. This lack of resources may be part of the explanation for why a relatively large amount of time was spent by study participants in child/eldercare. A similar explanation may account for the large number of activities associated with food preparation. In urban centres, it is possible to eat out at a restaurant or order food to your home. This option often does not exist in smaller communities. Interestingly, the practice of making extra food and selling it to

other community members through the community TV channel was discussed in some diaries and appeared to be the northern equivalent of ordering "take-out."

A number of limitations to this study must be noted. First, our sample contained more women than men and therefore was likely biased towards female activities. This may be another reason for the predominance of tasks such as food preparation and child/eldercare. It may be helpful in the future to engage a larger group of males to report on their activities to establish if there are consistent gender biases in activities. As well, the fact that diary completion was an open-ended activity led to a great deal of variability in what types of activities were reported. Some individuals discussed personal care such as bathing or brushing teeth while others did not mention these things at all. This variability is likely due to participant belief that the activities are either too mundane to report or too private. Regardless, very little information was gained about personal care activities from this group. This was also true for paid job activities. Some individuals reported working at the band office or at a nursing station while others did not mention any paid work at all. As paid work was not the focus of this study little information on this was gathered and it was not possible to establish how many individuals had paid work activities.

A final issue is the generalizability of these findings to other individuals in First Nations communities in the North.

Because this study involved a relatively small sample it is likely that it does not capture all of the different roles and activities that individuals have in a community. As well, because only five of the over 140 First Nations communities (Government of Canada, 2011) across Ontario were included, the results are likely not representative of all communities. A larger sample would allow for more detailed analysis of different practices across the more and less remote communities as well as an examination of differences between groups. Another issue related to generalizability is that only those fluent in written English were included. This very likely led to a bias against including individuals most fluent in their own languages as well as those without formal English education. Future

researchers might attempt to include these individuals by using alternative data collection methods such as providing digital tape recorders to participants and/or having researchers fluent in First Nations languages interview respondents. Another research method that may be useful for this purpose is focus groups. A focus group could include individuals from different communities brought together to discuss their daily activities. This method would allow for a collection of greater detail regarding activities as well as an opportunity to discuss information and clarify ideas directly with the participants.

Key Messages From This Article

People with disabilities: It is important for professionals to understand what kinds of things you can do for yourself and what kind of things you need help doing. Understanding the kinds of skills needed in each community will help professionals ask better questions about your skills.

Professionals: Current scales measuring ADLS are not always valid for remote or rural communities. Gathering information about daily life in these communities will help with creating more valid and culturally appropriate measures.

Policymakers: Daily activities in remote First Nations communities are very different from activities in urban areas. Learning more about these activities and ultimately creating more culturally appropriate measures will allow for more valid, standardized assessment and identification of individuals eligible for support services.

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