Identifying the gap in Assessing Activities of Daily Living in Resource-Constrained Rural Settings An Integrative Review of Existing Frameworks and Instruments

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Abstract

Introduction:

The non-availability of indoor piped water and electricity results in alternate forms of personal care and domestic tasks in resource-constrained rural settings. This article examines the applicability of existing measures for the contextual assessment of basic

and instrumental Activities of Daily Living (bADLs and iADLs) in these settings.

Method:

An integrative review guided by the approach of Lubbe et al (2020) was conducted.

Structured database searches of CINAHL, Scopus and Sabinet identified published

articles since 1986 which were subjected to eligibility criteria. Microsoft Excel was used

to synthesize data.

Results:

The search strategy yielded 999 articles that met the inclusion criteria, from which 56 ADL

instruments were identified. No instruments suited to resource-constrained rural settings

were identified.

Conclusion:

Occupational therapists should consider that existing ADL frameworks and instruments

appear silent on the impact of limited access to household amenities in resource-

constrained settings. This constitutes epistemic injustice as many rural households

globally do not have potable water or adequate household energy supply. Global South

occupational therapy curricula must showcase contextually relevant ADL frameworks and

development of contextually relevant instruments should be prioritised.

Key words: ADL assessment instruments, rural, household amenities, epistemic injustice

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Introduction

Existing Activity of Daily Living (ADL) frameworks and assessment instruments were developed in the Global North and may be fundamentally flawed in that they have limited applicability to rural less-resourced contexts. Given that more than two billion people worldwide do not have access to safe potable water and a similar number use fuelwood as their primary household energy source, it is clear that significant daily occupations have historically been overlooked (1–3)

The household amenities available to people living in resource constrained communities differ significantly from those typically available in urban settings (4). When basic resources such as sanitation, electricity and water are not available in the home environment limited access to indoor bathrooms and domestic appliances affects participation in Basic Activities of Daily Living (bADLs) and instrumental Activities of Daily Living (iADLs) which become more difficult particularly for those with mobility difficulties (2,5,6).

Water and energy sources are arguably the most important amenities when it comes to the performance of bADLs and iADLs in rural contexts (7). For example, water and fuelwood collection were identified as necessary iADL occupations typical of a rural South African context (8). Likewise, drinking water is essential for survival, and a sustainable water supply impacts food security as it allows for the cultivation of vegetables and being able to keep domestic animals as a food source for domestic requirements (9,10). Water is also essential for the performance of personal and household hygiene tasks. Similarly, an adequate supply of electricity opens up the potential for a household to make use of labour-saving appliances, which have an impact on the way bADL and iADL tasks are done. The presence of an electrical geyser to heat indoor-piped water for personal hygiene and doing laundry would eliminate the necessity for fuelwood to heat water on a fire.

The disjunct between the environmental resources in less resourced contexts and the traditional ADL ontology presents challenges to occupational therapy service provision-(5,11). Occupational therapists are experts in assessment of individuals' performance in bADLs and iADLs including their occupational forms, performance patterns, habits, routines, methods, environmental context, and challenges regarding execution (12,13).

Activities of daily living are all tasks people carry out on a regular basis, as part of their day-to-day routines (14). While this definition may be broad enough to include work and socialisation tasks, a number of models and frameworks that form the basis of occupational therapy practice provide more specific classifications for bADLs and iADLs. One such framework, the Occupational Therapy Practice Framework IV (OTPF IV) was developed to describe these constructs for occupational therapy practice (13). The OTPF IV's development was informed by the International Classification of Functioning, Disability and Health (ICF) with its focus on biopsychosocial and socioecological approaches (15). As such, the OTPF IV reflects the occupational therapy profession's move in recent years towards a more multifaceted understanding of occupation as the profession's core concern (16).

Frameworks such as the OTPF IV (13) regard the term ADL as only referring to functional mobility and personal care, while others use the term to describe all activities performed in daily life. There are also differing views regarding the tasks included within the term iADL, with some older references to assessment instruments including hobbies, leisure, volunteer work and social tasks as iADLs, which is contrary to the OTPF IV classification (15,17–19). To complicate matters further, synonyms for iADLs include independent living skills, extended ADL and advanced ADL, the latter focusing on iADL tasks that are more physically demanding (16). It is therefore important to define the terminology being used to avoid confusion. In this paper, the terms bADL and iADL are used as described in the OTPF IV (13).

The aim of this integrative literature review is to interrogate existing bADL and iADL assessment measures and critique their application against the background of widespread limited access to water, sanitation and electricity in a rural less-resourced context. The limitations of existing ADL frameworks and assessment instruments are considered and recommendations for contextually relevant curriculum development, further research and ADL assessment instrument development are made.

Method

The integrative literature review follows five steps as described by Lubbe et al. (2020). The review question was formulated (Step 1) using the PICOTS as follows: 'Do ADL scales and instruments commonly reported in the literature in the last 35 years, include

domains or items for comprehensive assessment relevant to rural resourced constrained contexts in South Africa?'.

The sampling of the literature (Step 2) included searching, screening and selection of research articles in peer reviewed journals and was limited to English abstracts and reports where an ADL instrument was used for data collection with scores reported. Multidisciplinary articles were included as ADL is reported as a broader construct with extensive literature across numerous disciplines. The keywords 'ADL instruments' AND 'ADL scales' OR 'iADL instruments' AND 'iADL scales' were utilised and revealed numerous articles from 1986 to August 2023. The database searching identified 270 publications on CINAHL, 376 on SCOPUS and 353 on Sabinet Online. The abstracts and methodology sections were screened by the first author for evidence that an ADL instrument was used for data collection. Excluded literature comprised scoping and systematic reviews and research articles in languages other than English and where an ADL or iADL instrument was not utilised for data collection in the study. No disputes occurred in the identification of articles which met the inclusion criteria.

For the critical appraisal (Step 3) articles with methodologies were included if the results reported scores for total or domains and items on an ADL or iADL instrument (13).

The data extraction and synthesis (Step 4) was then completed. according to a Microsoft Excel data extraction sheet which included authors, date, publication, ADL and iADL instrument/s used, country in which the instrument was developed, location of study, methodology, reported validity and reliability studies for the instruments and domains and items reported in the instruments. Where multiple ADL instruments were used for data collection in a study, all instruments were recorded.

Data synthesis was achieved with the analysis of three components of the ADL and iADL instruments. This included identifying the frequency with which the instruments were reported in the literature. Since many instruments were only utilised in a single study, only the ten most frequently cited instruments with referenced validity and reliability studies, which were reported in at least three studies were included in this integrative review. The validity and reliability studies for each instrument was included.

South African studies reporting of these ten ADL or IADL instruments were extracted to establish if rural contexts were considered in local research. Finally, a textual analysis to

identify ADL and IADL assessment instruments' items and domains that overlapped with the bADLs or iADLs as described in the OTPF IV (13) was completed.

The final step (Step 5) included the presentation and discussion of the data for the ten ADL or iADL instruments as described in Step 4 (20).

Results

A total of 56 assessment instruments and scales that were used for data collection and had domains or items that overlapped with the bADLs or iADLs as described in the OTPF IV (13) were identified. The frequencies of the instruments and scales utilised in the studies were calculated, with those cited in three or more studies being presented in Table 1

Table 1 Frequencies of bADL and iADL Instruments cited in literature search

Country of origin	Instrument name	Number of publications (N = 91)	Percentage of publications
United States of America	Katz Activity of Daily Living Index (21,22)	37	41%
	Barthel Index (and Modified Barthel Index) (23–26)	15	16%
	Lawton Instrumental Activities of Daily Living (IADL) Scale (27)	12	13%
	Stroke Impact Scale (17,28)	4	4.5%
	Functional Independence Measure (FIM) (29–32)	4	4.5%
	Activities of Daily Living Questionnaire (ADLQ) (33,34)	4	4.5%
		Sub-total:	83.5%
United Kingdom	Nottingham Extended ADL (35)	5	6%
	Modified Rankin Scale (19)	4	4.5%
	Frenchay Activities Index (36)	3	3%
		Sub-total	13.5%
Canada	Canadian Occupational Performance Measure (COPM) (37)	3	3%
		Sub-total	3%

Many of these identified articles made use of multiple bADL and iADL instruments and scales and included descriptive cross-sectional surveys with examination of functional or disability status, outcomes of clinical interventions, as well as validation of new and existing instruments. The Katz Activity of Daily Living Index (41%), the Barthel Index (16%) and the Lawton Instrumental Activities of Daily Living Scale (13%) were by far the three most frequently cited instruments, together comprising 70% of those most commonly utilised. All but two of the 56 bADL and iADL assessment instruments identified were found to have been developed in countries from the Global North and none included items or domains which accommodated the household amenities typical of less-resourced contexts.

Of the 56 assessment instruments and scales identified in the literature search, eight had been utilised in South African studies (Table 2). One instrument, namely the Modified Barthel Index (MBI) was the subject of a validity study for the South African stroke population (5) and subsequently used for data collection in a study on treatment of traumatic brain injury (38), while two were developed and validated in South Africa (18,39).

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Table 2 bADL and iADL Instruments used in South African studies

0	Clinical outcomes studies	tudies		Epidemiological surveys	ical surveys	SA- deve	SA- developed scales
12				4			
Barthel Index (and Modified Barthel Index) (23–26)	Functional Independence Measure (FIM) (29–32)	Modified Rankin Scale (19)	Stoke Impact Scale (17,40)	Katz Index of Independence in Activities of Daily Living (21,22)	WHODAS - 2.0 (41)	BETA nursing scale (bADL) (18)	GAMMA nursing scale (iADL) (39)
5		Count	ry where origin	Country where originally developed			
United States of America	United States of	United Kingdom	United	United States of	Switzerland	South Africa	South Africa
	America		States of America	America			
			South African studies	n studies			
(5,38,42–46)	(47,48)	(43)	(42)	(49,50)	(51–55)	(18)	(39)

Table 3: Comparison of Domains in OTPF IV and bADL and iADL Instruments used in South African studies

OTPF IV Domains	Domains and /or items present in bAI and iADL Instruments used in South African studies (n = 8)	
	Frequency	Percentage
	ADLs	
Bathing, showering	7	88%
Dressing	6	75%
Feeding	7	88%
Personal hygiene and grooming	4	50%
Toilet hygiene	6	75%
Bowel and bladder management	4	50%
Personal device care	0	0
Sexual activity	0	0
Transfer	7	88%
Mobility	7	88%
	Average	60%
	ADLs	
Child rearing	1	13%
Care of pets	0	0
Communication management	4	50%
Community mobility	4	50%
nancial management	2	25%
Health management and maintenance	1	13%
Home establishment and management	4	50%
Meal preparation and clean-up	2	25%
Religious observance	1	13%
Safety and emergency maintenance	0	0
Shopping	2	25%
	Average	24%

A comparison of the domains and items in the eight instruments utilised in South African studies with those in the OTPF IV is presented in Table 3. Significant overlap between the domains and items included in these instruments, and the bADL section of the OTPF IV was notable. Most (88%) included equivalents of bathing or showering, feeding and functional mobility, and 75% including equivalents of dressing and toilet hygiene. The overlap of iADL domains and items was lower, with 50% of the instruments including communication management, community mobility, and home establishment and management respectively. In terms of meal preparation and cleanup, 25% of the instruments were found to include equivalents.

Greater overlap was noted with bADLs than iADLs, where the average overlap was 60% and 24% respectively. Utilising principles of activity analysis, items and domains particularly reliant on access to water and household energy were identified, as shown in the highlighted sections of Table 3 (7). Of these, bathing, feeding and mobility were found to include equivalents in 88% of the assessment instruments, 50% included equivalents of home management and 25% included meal preparation and clean-up.

Discussion

Suitability of instruments for less-resourced rural contexts

The instruments and scales identified in this study focus on either bADLs or iADLs, with some focusing on both, which was similar to the finding of a systematic review of bADL and iADL scales used with neurological conditions (56). Scrutiny of the assessment instruments and scales identified in the literature search reported on in this paper demonstrated that there was substantial overlap with domains and items of the OTPF IV. However, it was notable that collection of water and fuelwood were not included in any domains or items in the instruments used to measure occupational performance in bADLs and iADLs, particularly those where access to water and energy are essential pre-requisites. Several of the studies did however make mention of the limited access to piped water, electricity and sanitation in the literature, study setting or discussion sections (49,50,52,55,57).

Eight South African studies used ADL measures to investigate the clinical outcomes for survivors of stroke. The Barthel Index (BI) was used in all these studies, while the Modified Rankin and the Stroke Impairment Scale (SIS) were each also used once. Of the studies that utilised the Barthel Index, only one made mention of participant's reports regarding the challenges relating to water collection (43). This study was set in the Eastern Cape Province and included an assessment of the impact of environmental barriers using the Facilitators and Barriers Survey (FABS) of environmental influences on participation (58). While inclusion of the measurement of environmental barriers is regarded as a strength of the study, the FABS was developed in the USA and was not modified for the South African rural context prior to the study. As the FABS does not have items regarding water and fuelwood collection, these aspects were not included in the data.

Usefulness of modified versions for rural South African settings

Modified versions of bADL and iADL assessment instruments have been produced for use in different countries. The Barthel Index (BI) is widely used and is regarded as the bADL assessment instrument of choice in many settings worldwide, with numerous modified versions being utilised (24,26,59). Where modified versions of the BI assessment instrument have been created for different countries, validity studies have utilised methodologies focused only on language translation. In identifying linguistic differences regarding bADL task item descriptors, some authors have also commented on the need for conceptual translation as several differences in the way a bADL task was conducted were uncovered. For example, numerous studies found that the term bathing was inappropriate in cultural settings where personal hygiene was achieved by using a damp cloth to wash the body, rather than making use of a tub or a shower. Another study reporting on the Chinese modification of the BI noted that some mobility items were not translatable due to constraints imposed by specific physical environments.

Modifications of the BI have focused on language with few attempts to change instrument items to accommodate for alternative ways of doing bADLs due to differing household amenities. The implications on the degree of physical demand of conducting the bADL task in these different environments were noted, but the authors only recommended modifications to certain item descriptors and fell short of eliminating irrelevant items or adding new ones (5,24,26,59). Most validity studies associated with the development of the modified versions of the BI identify minimal attention paid to differing cultural practices as a limiting factor.

The differences in the way South Africans living in non-Western contexts carry out bADL tasks was explored in a recent validity study on the applicability of the Modified Barthel Index (MBI) to the South African stroke population (5). Two factors leading to bADLs being done differently in these contexts were identified, namely resource and accessibility barriers. Limited access to running water and electricity within households was linked to socio-economic status and led to increased demands in terms of carrying out bADLs. Examples include emptying out a basin of dirty water after completing personal hygiene, as well as walking over rough terrain to reach outdoor toilet facilities. Given the limitations in access to water, sanitation and electricity described earlier, it is not surprising that the functional mobility domain was ranked highest for inclusion in

the South African version of the MBI. They recommend the addition of an item to reflect obtaining supplies necessary to carry out bADLs. While the author concluded that the MBI could be appropriate for the South African stroke population, the importance of the MBI not assuming a Western bias in terms of household amenities was emphasised (5). Thus, despite having been modified, many instrument domains and items remain inappropriate for rural settings in South Africa, and some important items and domains appear to have been completely omitted.

Increased physical burden of daily activities in rural contexts

Five of the South African studies were epidemiological and aimed at evaluating the associations between functional disability and various social and health status variables (52–55,57). These studies used the WHODAS-2.0 as one of the data collection instruments. The study by Schatz et al (2018) conducted in the Agincourt area in the Limpopo Province referred to older persons carrying out strenuous household activities such as collecting water and firewood. The socioeconomic status (SES) score, which includes access to water, sanitation and electricity, was included as a variable in the study. Gender role disparities in terms of care responsibilities, including 'strenuous activities', are mentioned and the need for further research regarding the factors linked to disability in the aging population are acknowledged (57).

In a further study also carried out in Agincourt, 42% of participants reported experiencing musculoskeletal pain, and the high musculoskeletal pain scores correlated with bad or very bad functional ability according to the WHODAS-2.0 (54). In a study carried out in the KwaZulu-Natal Province, water collection was reported as the activity for which most assistance was needed, with 93% of those that reported receiving care stating that they needed help with fetching water (51). Their study made recommendations for community support systems to assist older people with strenuous activities like drawing water. Realistic assessment of walking distances typically required for water and fuelwood collection in rural contexts is therefore necessary to enable occupational therapists to make impactful recommendations.

Inadequacy of standard walking tests for rural contexts

Water infrastructure in rural South Africa is built in accordance with the Reconstruction and Development Programme (RDP) Water Policy for domestic water supply, which

states that potable water needs to be within 200m from each dwelling (60). It follows that most rural dwellers need to be capable of walking a distance of at least 400m to allow for the round trip to collect their daily water needs and that standard walking tests should reflect this requirement.

The Stroke Impact Scale mentions 'walking one block' (17), while the WHODAS-2.0 refers to 'Walking a long distance such as a kilometre (or equivalent)' (41). However, not all instruments used in South African settings in the publications in this integrative review considered walking distances realistic for rural settings. Self-report and objective measures of mobility were used in the two Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa (HAALSI) studies (49,50). The Katz Index of Independence in Activities of Daily Living has a question about 'walking across a room', which was changed to 'walking a distance of 100m'. The objective measure was a timed walk, with walking speed being measured over only 2.5m distances. Walking and mobility were the bADLs with the highest level of reported impairment in a number of the clinical outcomes and epidemiological South African studies (43,50,53). Given that walking mobility is a prerequisite for completion of water and fuelwood tasks, presumably a walking impairment could translate into difficulties with collecting from sources outside of the homestead. Although some studies included variables known as Household assets and Socioeconomic circumstances, which included availability of piped water, electricity and sanitation, none of the studies carried out directly examined an association between household amenities and walking or mobility impairment (52,55).

The analysis of the literature regarding bADLs and iADLs in less-resourced settings in South Africa and globally is important as it highlights a gap in assessment instruments that do not take the bADL and iADL tasks typical of the rural context into account (5,6,11). The validity and reliability of existing instruments are therefore called into question when applied in rural populations further compounding some occupational therapists limited understanding of environmental factors such as the rough terrain and limited infrastructure that impact their clients' ability to perform daily activities (7,11). South African occupational therapists currently have no alternative but to base their professional opinions regarding recommendations for rural dwellers regarding reasonable accommodations, assistive devices and caregiving requirements on bADL and iADL assessment instruments that were developed in Western, well-resourced

countries (13,15,16,61,62). At best, this shortcoming illustrates the need for the development of a contextual bADL and iADL assessment instrument performance that takes contextual factors into account to ensure the provision of appropriate interventions for rural dwellers. More realistically, it highlights the need for occupational science and therapy disciplines to apply critical reflexivity and unpack taken-for-granted assumptions regarding household amenities on a global scale (63–65). The hegemony implicit in the assumption that ADL instruments formulated for well-resourced Western contexts have global utility is arguably a form of epistemic injustice.

Limitations of the study

Using only English language articles may have biased the results as articles from the Global South may have been excluded from the literature search.

Conclusion

Despite limited access to water, sanitation and energy being global issues affecting billions of people, the daily task of accessing these essential resources does not appear to be included in commonly used bADL and iADL assessment tools. It is therefore critically important to enable occupational therapists to accurately evaluate performance in bADLs and iADLs in a range of contexts, including those in rural less-resourced areas with limited household amenities.

The historical exclusion of the impact of limited access to household amenities on bADL and iADL performance from assessment instruments and occupational therapy frameworks is arguably an example of epistemic injustice and a manifestation of the pervasive bias towards Western and well-resourced contexts. The findings of the current study can inform and support the drive towards more inclusive South African undergraduate occupational therapy curricula. The review of ADL frameworks and assessment instruments that are taught will ensure that South African graduates are equipped to provide contextually relevant intervention.

Further research into the factors affecting the type and form of bADLs and iADLs in less-resourced rural contexts to inform the revision of ADL instruments is recommended. The development of a valid, cost-effective, contextually relevant South African bADL and iADL assessment instrument appears justified. The identification of

the gaps in occupational therapy frameworks and bADL and iADL assessme is important for the practice of occupational therapy in South Africa and international Africa and International Africa and Int	nt tools tionally.
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