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## Original Paper

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### Use of the ICF in Measuring Performance of Basic Activities of Daily Living in People living with HIV/AIDS in Two Selected Home Based Care Programmes in Lusaka, Zambia.

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#### Abstract

**Introduction:** The increase of access to antiretroviral therapy has led to prolongation of life among people living with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). Home based care is cost effective and convenient in managing HIV/AIDS. High prevalence of activity limiting symptoms has been reported in HIV/AIDS, but the level of performance of basic activities of daily has not been done in home based care programs in Zambia. The aim of this study was to measure the performance of basic activities of living in the Physiotherapy in Palliative Care Programme (PPCP) and Archdiocese of Lusaka (AL).

**Methods:** A descriptive cross sectional study design was carried out in PPCP and AL in Lusaka, Zambia. A total of 512 participants were recruited for the study and 481 questionnaires were returned, while 430 were eligible for analysis with two equal samples for each program. The International Classification of Functioning, Disability and Health (ICF) was used to measure the severity of symptoms and level of performance of mobility and self-care. Data were analysed using SPSS version 20. The student *t* test was used to determine whether performance was significantly different between the two programs.

**Results:** There were more females (69%) than males (31%) with an age range of 18 to 65 years (mean age: 40.56; SD=10.14). The majority of participants were single (57%) and 43% were married. The mean number of months on HBC was 36.87 (SD=23.93) for PPCP and 45.00 (SD=32.67) for AL participants. The mean number of months on ARVs was 45.93 (SD=26.02) for PPCP and 43.27 (SD=28.43) for AL participants. Pain was the most common symptom (69.5%) accounting for 72% in PPCP and 67% in AL. Other common symptoms were general fatigue (60.5%), numbness and tingling (55%) and tiring easily (53%). Participants scored 42.9% and 29.5% for mobility and 57.2 and 26.0% for self-care in PPCP and AL respectively. The overall performance of BADLs had a similar pattern (45.8% and 31.9%) and age and severity of symptoms significantly increased limitations in BADL.

**Conclusion:** People living with HIV/AIDS experience a lot of pain and problems in performing basic activities of daily living. Physiotherapy may help to improve performance in self-care activities. Increase in age and severity of symptoms can significantly increase limitations in BADL. There is need to research further using bigger sample and interventional studies. The ICF has proven to be a useful tool for PLWHA in Zambia.

**Key words:** Basic Activities of Daily Living, ICF, Home Based Care, Rehabilitation, HIV/AIDS

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## 1. Introduction

With longer survival period achievable with antiretroviral therapy (ART) combined with other medical advances and psychosocial support mechanism, the prognosis of HIV patients has changed from invariable death to a manageable near-normal life expectancy [1]. However, people living with the human immunodeficiency virus (HIV) infection are facing a multitude of health-related dysfunctions due to HIV and its associated concurrent health conditions [2]. The longer people living with HIV/AIDS (PLWHA) live, the more their relatives have to do basic activities of daily living (BADLs) for them [3]. The experience of living with HIV is compounded by the episodic nature of the HIV related disability that ultimately affects the performance for BADLs [4,5]. Although HIV/AIDS related disability and need for rehabilitation services have been acknowledged [1], few rehabilitation professionals work with PLWHA [6].

The Sub-Saharan Africa remains the region most heavily affected by HIV. In Zambia, the HIV prevalence stands at 14% among adults aged 15 to 49 years [7]. The number of PLWHA has continued to increase, due to the increase in population size and the scaling up of access to ART [8]. In Zambia, for example, 78% of the people eligible for antiretroviral drugs (ARVs) were receiving the drugs by mid-year 2010, just two percent below the universal access target of 80% ARV coverage [8]. It has been hypothesized that the widespread scale-up of ART in Sub-Saharan Africa will trigger increased experiences of disablement related to HIV [9]. As a result of advances in treatment, HIV infection now translates into various chronic dysfunctions and disabilities [10]. Neurological complications are among the important causes of morbidity and disability in the HIV infected population with a 15.8% prevalence dominated by central nervous diseases such as encephalitis, dementia and stroke [11]. A study done in British Columbia reported a 90% physical activity limitation among PLWHA [12]. In a study done in the United States of America, Terzian and colleagues found that HIV positive women are three times susceptible and have higher frailty prevalence than HIV negative women [13].

Pain from HIV associated peripheral neuropathy could be debilitating [14]. Neuropathic pain and HIV-sensory neuropathy remain prevalent, causing substantial disability and reduced quality of life (QOL) even with successful combined ART. In a study done in the African-American settings in the United States of America, it was found that apart from pain, fatigue is one of the most common activity limiting symptoms of HIV-positive individuals [15]. The consequences of fatigue include having to stop working, limiting one's involvement with family and needing an entire day to get through the simplest of household chores.

Home based care (HBC), mostly through community based care givers, has emerged as an effective method of providing cost-effective and compassionate care to those infected with HIV and suffering from AIDS [16]. Several HBC programmes in Zambia focus on preventive measures, treatment and psychosocial support to patients and their families with little attention to the BADLs [17,18]. On the other hand, the

national standards for training HBC workers, have placed much emphasis on physical comfort rather than functional ability despite outlining most of the symptoms and impairments amenable to physiotherapy [18,19]. A compilation of abstracts of studies done in Zambia on HIV/AIDS [17] shows that there has been little research activity in the area of HIV/AIDS related disability and particularly measuring the functional levels in BADLs. Evidence on HIV related impairment and disability is mostly descriptive and buried in the medical model as signs and symptoms [4,20]. Myezwa and co-researchers used the ICF on PLWHA and found that mental functions presented almost similar problems, with sleep (50%), low energy and drive (45%), and emotional functions (49%) [21]. The ICF is a useful in clinics that work hand in hand with rehabilitation teams. Van As and colleagues [22] used it in the clinic and reported that PLWHA had mental dysfunctions (69% (n=31), pain 71% (n=32), digestive and metabolic functions 45% (n=20) and neuromuscular problems 27% (n=12) while at activity level, there were limitations in mobility 40% (n=18) and general tasks and demands 38% (n=17). The ICF was used to assessed HIV positive in-patients and found a high prevalence of both functional and activity limitations in neuromusculoskeletal (73.8%); mental (72.6%); energy and drive (75%); sleep (71%); emotional (62%), and muscle power (75%), mobility (56.4%), major life areas (55.1%), and community, social and civic life (50%) [21]. In another of the scoping the IFC was used to measure the actual level of function in a cohort study in South Africa which found that 14.2% of participants scored at a mild level on one limitation and 35.6% of the sample experienced at least moderate to severe activity limitations with two or more scores on the WHODAS [23].

There has been little research in both the disabling nature of HIV/AIDS and the extent of disability in Zambia [19-21]. Some studies have measured the functional ability of PLWHA using the ICF but reported their findings as ratios and frequencies. There have been few studies that have measured functional activity but have not measured BADLs. The settings in which the functional capacity of PLWHA has been assessed have been different. None of the studies has measured the BADLs in HBC programmes in Zambia. The aim of this study therefore was to measure the performance of BADL in PLWHA in HBC programmes using the ICF.

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## 2. Methodology

Upon obtaining approval from the University of Zambia Biomedical Research Ethics Committee, permission was sought from the Director of Physiotherapy in Palliative Care Programme (PPCP) and Archdiocese of Lusaka (AL) HBC Programme Manager to carry out the study. Informed consent was obtained from study participants and no personal identifiers were used in the study. Further, the study did not interfere with the management that the participants were receiving during and after the study.

A descriptive cross-sectional study design was undertaken. Five hundred and twelve (N=512) HIV positive participants on HAART were selected using systematic random sampling from two HBC programmes: PPCP (n=256) and AL (n=256). Participants from PPCP were receiving physiotherapy from community care givers apart from HBC services while participants from AL received typical HBC as prescribed by the Ministry of Health.

An ICF derived questionnaire with three sections (A-C) was used to collect data. Section A comprised demographic data while B and C, domains of the ICF covering symptoms experienced by participants and performance of BADLs, measures of body structures and body functions and the overall functional levels. Research assistants were trained in

the use of the questionnaire for data collection. Participants were scored on both presence and severity of nine symptoms, mobility and self-care activities. The total score on symptoms had a possible maximum of 38 and mobility and self-care 48. Data was analyzed using the Scientific Package for Social Sciences (SPSS) Version 20.0 software with the level of significance set at 95% CI. Pearson’s correlation test, student *t* test, linear regression and the two way analysis of variance (ANOVA) were used for analysis.

### 3. Results

#### 3.1 Demographic Characteristics

A total of 481 questionnaires were returned, but 51 were excluded for analysis due to lack of completion and facilitation of the attainment of two equal samples from the two selected programs. Therefore, only 215 participants from PPCP and 215 from AL were picked for the analysis thus giving a response rate of 92.3%. The majority 295 (69%) were females while the age range was from 18 to 65 years and mean age was 40.56 years with a SD of 10.14 (SD). The mean age for PPCP participants was 42.06 (SD=10.34) and 39.06 SD=9.94 for AL participants. The majority of participants (245) were single and 185 were married. The majority (n=291) of participants were household heads (house-hold head does not mean home owner as described in table below). The mean number of months on HBC was 36.87 (SD=23.93) for PPCP and 45.00 (SD=32.67) for AL participants. The mean number of months on ARVs was 45.93 (SD=26.02) for PPCP and 43.27 (SD=28.43) for AL participants. Table 1 presents demographic characteristics of the participants.

**Table 1:** Demographic Characteristics of all the participants in the study (N=430)

| Variable              | Frequency | Percentage |
|-----------------------|-----------|------------|
| <b>Gender</b>         |           |            |
| Female                | 295       | 68.6       |
| Male                  | 135       | 31.4       |
| <b>Family Role</b>    |           |            |
| Head of the family    | 291       | 67.7       |
| Dependant             | 239       | 32.3       |
| <b>Marital Status</b> |           |            |
| Married               | 185       | 43         |
| Single                | 245       | 57         |

#### 3.2 Activity limiting symptoms experienced by participants in both programs

Symptoms experienced by the participants were generally more common among PPCP than AL participants (figure 1). Pain was the commonest symptom (69.5) accounting for 72% in PPCP and 67% in AL. Other common symptoms were general fatigue (60.5%), numbness and tingling (55%) and tiring easily (53%). Symptoms were generally mild to moderate (n=200 and n= 135 respectively).

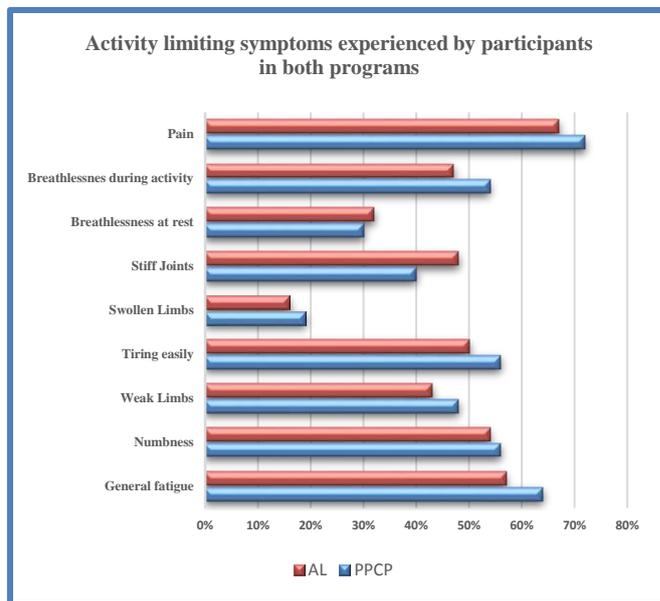


Figure 1: Activity limiting symptoms in both PPCP and AL

The symptoms were mostly mild to moderate (46% and 31.5%) respectively as shown in figure 2. Fifty percent of the participants in PPCP had moderate to worst symptoms while more than 60% of the participants in AL had symptoms that were below the moderate mark. Most of the participants in both PPCP and AL had no to mild mobility and self-care problems (42.9% and 29.5% for mobility and 57.2 and 26.0% for self-care). The overall performance of BADLs had a similar pattern (45.8% and 31.9%). Comparatively, of the PPCP participants, 74.5% (29%+25.5) had no to mild mobility problems compared to 70% in AL. In self-care activities 76% of the PPCP participants had no problems while 13% had mild problems.

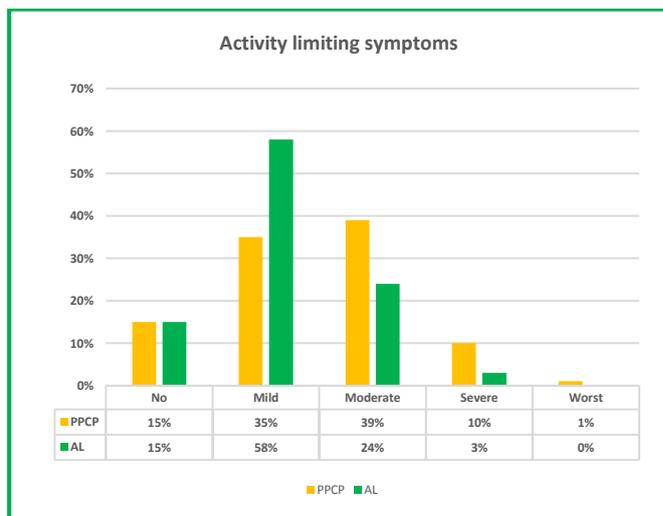


Figure 2: Frequency of activity limiting symptoms according to severity.

### 3.3 Performance of Mobility and Self-care among participants in PPCP and AL

The PPCP programme had a few (0.5%) participants who were completely dependent in both mobility and self-care activities. Forty-seven percent of the AL participants had moderate to severe mobility problems (24% + 13%) compared to PPCP (23%) (Figures 3 and 4). In self-care activities, there were 42% (36+6%) with moderate to severe limitation compared to 16% (11+5%) in PPCP. In the performance of BADLs (mobility and self-care) 81% (52%+31%) participants had no or mild problems compared to 72% (39% + 33%) in AL. About (60%) of the participants in AL had moderate to severe problems in performing BADLs compared to 14.5% (9%+5.5%) in PPCP. Why discuss mobility and self-care together? They are 2 different things, hence combining their results is confusing.

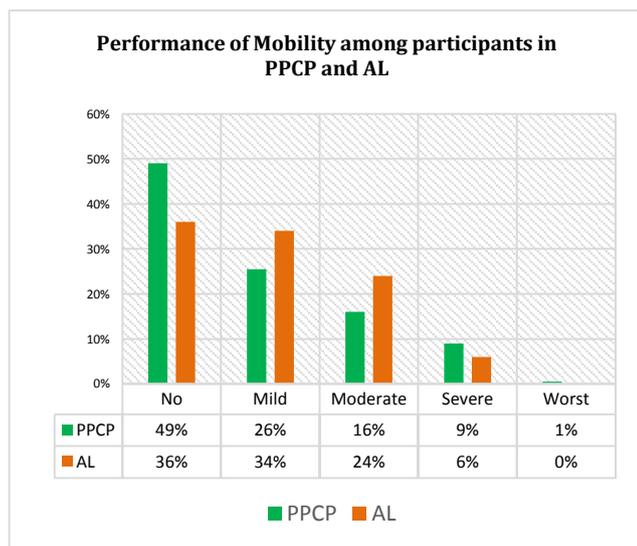


Figure 3: Performance of mobility among PPCP and AL participants.

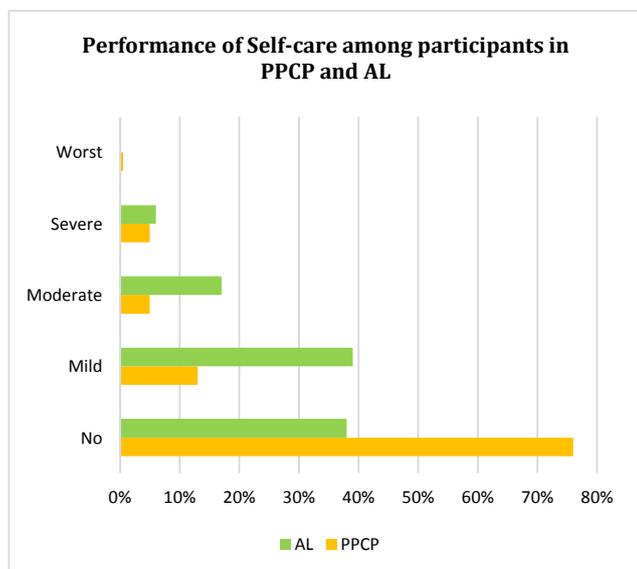


Figure 4: Performance of self-care among PPCP and AL participants

### 3.4 General Performance of the two groups

Using an independent samples *t* test, it was found that participants in PPCP had significantly severe symptoms compared to AL participants ( $p = 0.001$  one tailed,  $t = 4.739$  at a 95% confidence interval of 1.601 and 3.869). There was no significant difference in the performance of BADLs between participants from PPCP and AL ( $p = 0.114$ ,  $t = -1.583$  at 95% confidence interval of 0.321 and -2.981). There was no significant difference between PPCP and AL participants in mobility capacity ( $p = 0.789$ ,  $t = 0.255$  at a 95% confidence interval of 1.415 and 1.09). There was a significant difference in the performance of self-care activities between participants in PPCP and AL. ( $p = 0.005$  one tailed,  $t = 3.858$  at a 95% confidence interval of -1.945 and -.632). Participants under AL had been significantly longer on HBC ( $t = -2.946$ ,  $P = 0.005$  at a 95% confidence interval of -13.563 and -2.707) while participants under PPCP were significantly older than those under AL ( $t = 3.066$ ,  $P = 0.005$  at 95% confidence interval of 1.077 and 4.923).

Age and severity of symptoms were significantly correlated with performance of BADLs at  $R = 0.163$   $p = 0.001$  two tailed for age and  $R = .558$ ,  $p = 0.000$  two tailed for severity of symptoms. Using the two way ANOVA, it was found that there was no association between gender, family role (household head or dependent) and marital status (married or single) and the performance of BADLs ( $F = .004$  and  $P = .849$ ,  $F = .953$  and  $P = .330$  and  $F = .976$  and  $P = .324$  respectively.) Increase in age and severity of symptoms significantly increased the limitations in BADLs ( $r^2 = 0.027$ ,  $p = 0.001$  for age and,  $r^2 = .346$ ,  $p = 0.000$  for severity of symptoms). The ICF was capable of measuring symptoms, mobility and self-care capacity in PLWHA.

## 4. DISCUSSION

Activity limiting symptoms were found to be high among PLWHA in both PPCP and AL HBC programmes. In both PPCP and AL pain was the most common activity limiting symptom (72% and 67%) followed by general fatigue, numbness/tingling, tiring easily and breathlessness during activity. The findings of this study are similar to the findings of Myezwa who reported that 80% of participants had mild to severe pain [20] and Nair and colleagues reported a 79% pain prevalence in patient with stage III and IV HIV disease in hospice care [24]. Carr reported pain prevalence of between 60-70% among patients being cared for in hospices [25]. The prevalence of symptoms such as pain, general fatigue were higher among patients receiving physiotherapy compared to those who were not. These results are similar to the findings of other studies [20,24].

Most activity limiting symptoms arise from the effects of the HIV virus, ARVs and opportunistic health conditions on the nervous system [26]. Neuropathic HIV related sensory neuropathy remains prevalent, causing substantial disability even with combined ART [27]. In a case study in Canada by O'Brien and his colleague (2010), a patient with HIV/AIDS

and on HAART presented with peripheral neuropathy, fatigue and overall deconditioning after a bout of pneumonia [4]. Apart from pain, fatigue is found to be one of the commonest and debilitating symptoms of HIV-positive individuals that led to functional limitations [15] which was the second most frequent symptom in this study. Similar to this study, other researchers reported a high prevalence in muscle weakness, tiring easily and having difficulty with BADLs [13]. Fatigue, weakness and pain may arise from HAART. This is because certain ARVs such as nucleoside transcriptase inhibitors (stavudine, didanosine and zalcitabine) especially when more than one such agents are used in combination have side effects that might aggravate or cause symptoms [24,26]. All the participants in this study were on HAART for a minimum of six months although the combinations of the ARVs were not ascertained.

More than 40% (*figure 2*) of the participants in both HBC programmes had moderate to worst activity limiting symptoms. Participants from a physiotherapy incorporated programme (PPCP) had more severe activity limiting symptoms (39% + 22% + 2%) compared to 30% in AL (*Figure 1*). The difference in severity of activity limiting symptoms was statistically significant ( $P = 0.001$ ;  $t = 4.739$  at a 95% confidence interval of 1.601 and 3.869). These findings suggest that although symptoms were common and moderate to worst in both HIV home based care programmes, they were more prevalent and severe in physiotherapy incorporated HBC. The findings are consistent with findings of Myezwa and Nair and their colleagues who reported a higher prevalence of symptoms among patients receiving physiotherapy compared to those who did not [21,23]. The activity limiting symptoms arise from the effects of the HIV virus, ARVs and opportunistic health conditions on the nervous system [26,28]. The results of the current study showed that the patients in PPCP had slightly more severe symptoms in mobility although they received physiotherapy and this is confirmed by other studies [29,30] also. Other factors such as age may have influenced the differences in symptoms [31]. For example, advanced age alone is associated with a lot of disabling conditions such as diabetes, stroke, cardiac problems and degenerative neuropathies which in HIV/AIDS manifest earlier [31]. It is possible that the age of the participants in PPCP as well as the severity of symptoms influenced the performance of BADLs downwards because age in HIV/AIDS is a major determinant of the functional capacity [30]. This conclusion is based on the finding that PPCP participants were significantly older and had more severe function limiting symptoms which individually or combined significantly affect functional ability [30]. The findings in this study also indicate that the older a person the more the BADLs are negatively affected ( $p = 0.001$ ) and that the more severe the symptoms the less the performance of BADLs ( $p = 0.000$ ). These findings may also reflect a socio-economically importance especially that most of the participants ( $n = 206$ ) were female and at the same time house hold heads who needed to take care of themselves and other people in the home.

Even though activity limiting symptoms were more prevalent and significantly severe in PPCP ( $p = 0.001$ ,  $t = 4.739$ ) more than 70% of participants in PPCP had no difficulty in performing self-care activities (*Figure 4*). When compared with AL participants PPCP candidates were significantly better in performing self-care activities ( $t = 3.858$   $p = 0.005$  one tailed with a mean difference of -1.288 at a 95% confidence interval of -1.945 and -.632). The better performance of PPCP participants in self-care could be partly attributed to the aim and objective of physiotherapy which is to promote and encourage optimal independence regardless of the health status [32]. The PPCP participants may have been encouraged to perform self-care activities rather than being helped by care givers or relatives. This could have advantaged PPCP participants in the performance of self-care activities [33]. The case may have been different for typical HBC (AL participants) where instead of promoting independence, the HBC workers or relatives of the patients could have done most of the self-care activities for the patients in accordance with the training manual and national minimum standards for community based care where the responsibilities of a HBC giver include helping with feeding, bathing, dressing and undressing the patient [17]. A study that was done in Zambia challenged physiotherapists to produce evidence on the impact of the interventions given to patients with neuropathies on HAART [1].

The ICF tool was capable of measuring symptoms and BADLs of PLWHA and may hence be recommended for use in future studies in Zambia. This is the first time the use of the ICF has been reported in Zambia. The ICF is a very useful tool for use in describing functioning of all people, not only persons with disabilities [34]. Its usage by physiotherapists and other rehabilitation professionals on PLWHA has been reported by Myezwa and others [21] in Brazil and South Africa and Van and colleagues [22].

## 5. CONCLUSION

Activity limiting symptoms dominated by pain are prevalent among PLWHA in PPCP and AL home based care programme. The use of the ICF in measuring the performance of basic activities of living may be useful in understanding the level of performance and planning rehabilitation services. Increase in age and severity of symptoms can significantly increase limitations in BADLs. Physiotherapy seems to help PLWHA in performing self-care activities.

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at all the study sites, for their dedication and contribution to the successful data collection process.

## Abbreviations

|              |   |
|--------------|---|
| <b>ICF</b>   | <i>International Classification of Functioning, Disability and Health</i> |
| <b>AL</b>    | <i>Archdiocese of Lusaka</i>  |
| <b>BADLs</b> | <i>Basic Activities of Daily Living</i>                                   |
| <b>HBC</b>   | <i>Home Based Care</i>  |
| <b>PLWHA</b> | <i>People living with HIV/AIDS</i>  |
| <b>PPCP</b>  | <i>Physiotherapy in Palliative Care Programme</i>                         |
| <b>HIV</b>   | <i>Human Immunodeficiency Virus</i>                                       |
| <b>AIDS</b>  | <i>Acquired Immune Deficiency Syndrome</i>                                |

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