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Buang at Ulyanin: An Ethnographic Study on the Selected Cases of Schizophrenia and Dementia in Baseco Compound, Manila

INTRODUCTION

Mental health, according to the standardized meaning provided by the World Health Organization (2014), is a "state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community". Mental illness, on the other hand, is referred to as "a health problem that significantly affects how a person feels, thinks, behaves, and interacts with other people" (The Department of Health, Australian Government, 2016). In the Philippines, mental illness and disorders remain the third most common form of disability among Filipinos, succeeding visual and hearing impairments (Crisostomo, 2010). Previous studies have shown that regular medication and rehabilitation through psychological interventions and social interactions effectively minimize the degree of disability brought about by schizophrenia (Raj, 2013). Although in some less developed coping methods like the use of herbal medicines are noticeably making its way to the countries where different memory disorders [including dementia] are prevalent, alternative individuals' households (Chang et al. 2016; Perry and Howes 2011).

SCHIZOPHRENIA AND DEMENTIA

Schizophrenia is a severe chronic mental disorder affecting an individual's cognition and behavior manifested through disturbances in thinking and perceptions (Barbato, 1998). The illness ranks 7th as the world's leading cause of years lived with disability (Ayuso-Mateos, 2006) and, in its acute phase is also the highest disability among 291 diseases logged by the Global Burden of Diseases (McGrath,2016). In a study conducted by the

Philippine Health Information System on Mental Health, among the 2,562 patients that consulted 14 participating mental facilities, schizophrenia was found to be the most prominent mental disorder at 42% (Uy, 2015). The people suspected to have schizophrenia living in Baseco Compound, Manila, due to their financial instability, are highly dependent on government-issued health care. In 2007, Philippine government only provided 5% of the total health budget on the operation and maintenance of public mental health institutions[CG3] (World Health Organization, 2007) which result to the scarcity in slots among the few public mental health institutions in the Philippines (Francisco, 2014). However, in 2017, due to the proposed Mental Health Bill, the government will be allocating P220 million to the mental health program and P1 billion for the improvement of mental health facilities and rehabilitation centers in the Philippines. As such, individuals with mental illnesses still remain to have low access to the services provided by public mental institutions despite their proximity to these centers. With this said, this research paper explores and describes the household-based rehabilitation strategies provided by the individual's family members as an alternative to professional rehabilitation.

Dementia, on the other hand, is one of the most common chronic illnesses affecting 36 million people worldwide, and is also estimated to increase up to 66 million by 2030 and 115 million by 2050. This is not a disease exclusive to developed countries due to the fact that majority of the people who are affected by it usually inhabit lower and middle-income states (Bamford, Holley-Moore, and Watson 2014; Batsch and Mittelman 2012; Wimo and Prince 2010; Yasamy et al. 2012). It is predominantly associated and relative to the age of the individual which has a negative effect on their cognitive and functional abilities (American Psychiatric Association 1994 as cited in Phillipson et al. 2012). Traditionally, being diagnosed with dementia is perceived as a negative by the family members of the individual. This is mainly because of the attached stigma within the illness that affects not only the individual or the older adult, but also the household in which they reside in (Nuffield Council on Bioethics 2009). These are some of the reasons why the World Health Organization "recognized dementia as a public health priority" (Yasamy et al. 2012:5).

LOCALIZED CONCEPTS OF SCHIZOPHRENIA AND DEMENTIA

Health has always been a prevalent issue in the lower socioeconomic class as evidenced by higher morbidity and mortality rates due to chronic and acute illnesses that are typically resulting from low access to nutritious food and health services (Bloch et al. 2011; Lee and Frongillo, Jr. 2001; Mishra et al. 2013). Although despite the universal definition introduced by the World Health Organization, health is still perceived and conceptualized differently between cultures (Mishra, Kusuma, and Babu 2013).

Diagnosis of dementia sometimes varies between majority and minority groups primarily because of their cultural differences, along with the inequalities experienced by both groups with regard to their socioeconomic contexts (Forbat 2003:7).

By definition, stigma "results from a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against" (World Health Organization and Association 2002:8). The stigma of being associated with dementia does not necessarily end with the individual who possesses it, but also with their family members or the people who take care of them (Bloch, Rozmovits, and Giambrone 2011; Nolan et al. 2006). This is highly because of the community's misconstruction of the individual's condition (Forbat 2003:7–8). According to Mary Marshall in her work 'The challenge of looking after people with dementia':

> "People with dementia are very vulnerable. They cannot usually complain about their care, and if they try to communicate through their behavior, the response is often to see it as a symptom to be suppressed" (2001:411).

Internalization of the stigma faced by the dementia-inflicted individual is highly possible, which makes them think that they are at fault for their brain's impairment (Nuffield Council on Bioethics 2009).

Experiences of stigma among individuals with mental illnesses, in this case, schizophrenia, have affected their ways of living in terms of social interactions, work, and health care since the deinstitutionalization of mental health programs and centers (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002; Penn, Kohlmaier, & Corrigan, 2000; Shea, 2010). These social interactions may be ridden with stigmatization and discriminative reactions that could hinder full recovery of the individual (Penn,

Kohlmaier, & Corrigan, 2000; Shea, 2010). These social interactions may be ridden with stigmatization and discriminative reactions that could hinder full recovery of the individual (Penn, Kohlmaier, & Corrigan, 2000). This resulted to the attrition of their coping capacities and damage to the individuals with schizophrenia's sense of self (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). Although social interaction is a vital process in an individual's recovery, the social interactions and behavior of the people towards them must be taken into account for it could lead to further deterioration on the part of the individuals. Avoidance of self-disclosure and secrecy, about one' mental illness is the most common among the individuals' coping strategy due to their worry of being isolated and viewed unfavorably (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). Discriminative behaviors cause the individuals to withdraw from possible social interactions, thus diminishing further possibilities of rehabilitation and recovery. The process of reestablishing the individual's sense of self is being viewed as the key factor in facilitating an individual's recovery from schizophrenia. However, stigma of the community and the individuals perceived stigma hinder their rehabilitation, thus affecting their recovery (Shea, 2010).

POVERTY

The socioeconomic status of the individuals with schizophrenia contributes to the extent of stigma experiences. The respondents with perceived incomes low enough to be insufficient in meeting their basic needs contributed to their feelings of rejection and their intrapersonal stigma (Yow & Mehta, 2010). There has been an association between insecurity of income flow and mental disorders evident in the studies. In one of the studies, the impact of financial insecurity to mental health is relayed through an account of the suicide rate of farmers in India. Illiteracy is a widespread risk factor for mental disorders. The social consequences brought about by poor education have diminished opportunities for people with mental disorders, hindering them from accessing resources for the improvement of their situation (Patel & Kleinman, 2003). Due to poverty, family and relatives are the ones who engage in the individual's caregiving. Thus, family caregivers who are detached and distant experience less difficulties. On the other hand, the relatives who are more committed to the caregiving process perceived more

difficulties, but also, more rewards (Aggarwal, Avasthi, Kumar, & Grover, 2011).

COMMUNITY-BASED REHABILITATION FOR SCHIZOPHRENIA

According to the research, about a quarter and a third of individuals with schizophrenia and other severe cases of mental illnesses participate in psychosocial rehabilitation programs. However, the research argues that there is a lack of research on recovery in community-based psychosocial settings which poses a question as to how many of the individuals admitted to these rehabilitation programs actually has the potential to achieve periods of recovery (Lim, Barrio, Hernandez, Barragan, & Brekke, 2015; R., Baba, Heng Chin, & Hoe, 2003). Considering possibilities of being rehabilitated in a community-based rehabilitative center, the factor of social stigma associated with their illness may restrict or reduce chances of successful rehabilitation.

HOUSEHOLD-BASED APPROACHES FOR MENTAL ILLNESSES

In the context of the family members and caregivers of patients with dementia, difficulty in seeking treatment for the latter's condition is commonly experienced. This is mainly because of their insufficient knowledge on the appropriate services needed for dementia care (Prorok, Horgan, and Seitz 2013:3). This kind of behavior is also affected by "the availability, accessibility, affordability, and acceptability of the services to the patients who are in need of such" (Kroeger 1983 as cited in Atwine and Hjelm 2016:18). Although there is still no available cure for dementia, the family and the primary caregiver should be able to plan and seek assistance for the older adult's condition (Santacruz and Swagerty 2001).

According to the World Alzheimer Report in 2010, there is an increasing need for cost-effective strategies of coping with dementia in order for people to manage the cost of caring for this kind of illness (Wimo and Prince 2010). Some dementia patients who fail to seek formal treatment for their condition often resort to herbal medicines that are typically accessible over-the-counter (Alzheimer's Society 2003; Chang et al. 2016). This kind of method for coping with their condition is a cheaper way of alleviating the symptoms of dementia (Alzheimer's Association n.d.; Hughes, Mthembu, and Adams 2011; Perry and Howes 2011; Rabins et al. 2010).

SOCIAL SUFFERING

The study was framed using Arthur Kleinman's Illness as a Social Suffering (Kleinman, Das, and Lock 1997). Illness and injury are one of the few forms of suffering that are experienced by individuals (Kleinman 1998:375). Suffering is viewed not only as a personal experience, but also as a social experience which are caused by structures within the society that the individual is in (Anderson 2013; Kleinman 1998:391; Victora 2011). This manifestation of suffering constrains not only the demented older adults, but also their family members and neighbors, because of the structural vulnerabilities that arise (Kleinman 1998:377).

METHODS

RESEARCH DESIGN

For this study, the researcher used qualitative approach—specifically focused ethnography. The utilization of this kind of approach enriches the knowledge and understanding of the researcher on his chosen topic, while at the same time, gathering primary data through his experience in the field which will be manifested through several short-term visits (Spradley 1980 as cited in Browett 2012; Knoblauch 2005; Whitehead 2005). This required the researcher to immerse himself in the culture of his informants over an extended period of time (Higginbottom, Pillay, and Boadu 2013).

SAMPLING TECHNIQUE

The sampling technique used for this research is non-probability purposive sampling. This technique allowed the proponents to use their preferences in the selection of the informants based on the qualities that they possess. This also enabled them to acquire the participants for research with precision (Henry 1990 as cited in Latham 2007; Tashakkori and Teddlie 2003 as cited in Teddlie and Yu 2007; Tongco 2007).

An individual is invited to participate in the schizophrenia aspect of this research provided that he or she is: a) a family member and/or a neighbor of a female individual suspected to have schizophrenia; b) a resident of Baseco Compound; and c) currently not providing professional medical health care for the individual.

For the demented older adults, they should be: a) aged 55 and above; and b) living with at least one family member. For each key informant, one family member and three

neighbors were interviewed to ensure consistency within the gathered data.

DATA GATHERING TECHNIQUE

The technique used for the gathering of data of this particular study is participant observation that determines the patterns and differences of their rehabilitation processes present in their everyday experiences with mental illness, social interactions, and coping mechanisms. In-depth interviews were also conducted for clarifications and further verbal explanations from the informants which then serves as textual data in which its content have been analyzed.

In order to gather the primary data sought by the proponents of the study, audio recorders and semi-structured interviews were used to collect the participants' own opinions and experiences, with the former still having control over the process. The researchers made use of a guide containing the instructions, questions and topic areas needed to be covered to ensure that relevant information were gathered from the informants (Cohen and Crabtree 2006; Harrell and Bradley 2009).

FINDINGS

LOCALIZED LABELS FOR SCHIZOPHRENIA

When asked to name Alma's condition, Nanay Fely, her aunt and primary caretaker, referred to her as "*may something*" and "*may kuriring*" which she sees as a condition different from a person who is characterized to be "*siraulo*". She expressed that the condition of Alma, who is "*may something*", cannot be treated by mental institutions because she believes that only people who are "*siraulo*" and violent are the only ones that are allowed to be admitted to mental institutions. The term "*may something*" is also used by Jessica to characterize Alma. Jessica views her as "may something" and "*may konti*", not "*baliw*" or crazy, because of how Alma can fully function and even participate in conversations while implying that people who are mentally unstable are not able to joke around. This is evident in her statement: *"Ano lang siya, yung may konti lang siya pero 'di mo naman masasabing baliw kasi nakikipagbiruan pa sa'yo (...) nakakakilos siya, nakaka-paghugas, nakakapaglinis dito hanggang dun yan".*

As for Che, her daughter Sonia referred to her as, "*Hindi kagaya ng normal na tao na may*

dahilan yung tawa, may dahilan yung galit" [(She is) Unlike a normal person who has a reason for laughing, a reason for being angered] and also expressed that, "*Wala siya sa tamang pag-iisip noon." (*She was not in the right mind/thinking before.) Nanay Leonora, a long-time neighbor of Ate Che, pertained to her as someone who is, "*may diperensiya na*." [Already impaired (thinking).]

Dolor only terms her sister, Sheila, as violent ("*nananakit", "bayolente*") while acknowledging the possibility that she is possessed ("*sinapian*"). On the other hand, Alona, their neighbor and Dolor's best friend, expresses how she could not call Sheila as someone who is crazy and not in the right mind because it is just her condition that leads her to become that way while Luz, another neighbor, refers to Sheila as an impaired person or as Luz puts it, "*may topak*".

The neighbors and family members refer to the individuals with concepts that highlight the disparity between them, the normal ones, and the individuals. This highlights the social stigma present among the community towards them. They view the individuals as people who are different from them, despite being victims of social structures that disable them to participate in the social as well as physical activities that other members of society participate in.

LOCALIZED LABELS FOR DEMENTIA

"Bumabalik sa pagkabata"/"Balik bata"

Most of the informants of the study perceived dementia or being "ulyanin" as "bumabalik sa pagkabata". This is because of the child-like qualities being adopted by the older adults because of their condition's symptoms. Some of these include being moody and "makulit", which pose as a challenge for the family members and neighbors of the individual towards providing care and support for them.

Teresita, a single mother who lives in a household with 8 other people, when asked about the difficulty of providing care and support for her demented mother, answered with: "Mahirap talaga magpalaki ng mama." This statement is an ironic expression of how their roles as mother and daughter have switched due to the appearance of the former's dementia symptoms.

Ruth recounts of the times wherein Nanay Nelia would buy jelly candies from her sari-sari store whenever she sees children doing so. She says: *"'Yung binibili pa niya 'yung mga candy ng bata o kaya Joly. 'Yan 'yung mga... 'Pag nakita niyang bumibili 'yung mga bata ng Joly, maya maya bibili rin siya."*

Role-playing was seen as a significant aspect of Tatay Zosimo's condition by one of his neighbors, Jennifer. She mentioned of a time wherein Tatay would look for her husband and, "*Hinahanap niya 'yung asawa ko kasi kilala niya pala asawa ko. Ipapasok niya daw nang, ano, hepe ng mga tanod.* (laughs)."

REHABILITATIVE AND COPING STRATEGIES

During Alma's outbursts, Nanay Fely opts to let Alma be for she believes that countering Alma would only worsen her anger. This is evident in her statement:

> "Pinakikibagayan na lang kung anong gusto niya sarili niya, kung anong desisyon niya. Dahil pag pinatulan naman yan, wala rin. Pagka-ano, ipupukpok din yung ding – ulo niya sa dingding. Pinababayaan na lang siya." (We just act accordingly with whatever she wants for herself, whatever her decision is, because if we counter her, nothing will happen. She will just bang her head on the wall. We just let her be.)

Jessica, Angeline, and Mameng are neighbors of Alma who interact with her daily for they live in close proximity to her. They have express similar accounts in terms of Alma's productivity when it comes to household chores and livelihood. They often hear Alma's protests whenever she is asked to do chores, but they also narrated how Alma also takes the initiative to do chores.

According to Sonia, as well as their neighbors Leonora and Marlene, she is responsible for Che's check-ups at the National Center for Mental Health. She narrates how she makes sure that they go there for check-ups every two months as required by the doctor even though she struggles with their fare going there. Sonia implied that Che's stay in a mental institution has helped her in the statement, "Nung 'di pa siya nagagamot, kahit saan yan nagpupunta, hindi mapipigilan yan" (When she was not yet cured, she goes anywhere. Nothing can stop her.) Currently, Che's only task around the house is to take care of her grandchildren. They do not assign her chores anymore so as not to add stress on Che's part. The neighbors also took notice of this as they expressed how Che's condition post-treatment has returned to normal.

Dolor's family consulted numerous *albularyo* or faith healers to no avail for the faith

healers express that her case is irreversible, and that she is already irretrievably bound to a spirit. Dolor's family also resorted to admitting Sheila into a mental institution but after weeks of being confined, Sheila, with notable improvement, begged her family to take her home; however, the specialists in the institution gave them a warning that once they release Sheila without completing treatment, they may never admit her again The family gave in to Sheila's pleading then, however, they are currently intent on finding ways to readmit Sheila into an institution.

Dolor relayed how Sheila is violent, even to their family in the statement, "*Ta yung papa ko nga dati natanggal yung tainga eh. Tinabas niya tapos binato niya ng bote."* (My father's ear was cut off before. She sawed it and she threw a bottle at him.) Due to this incident, their father chained Sheila and put her in a closed-off room so as to avoid inflicting more harm unto others. Dolor and her other two sisters take turns with feeding Sheila, although they have difficulties in maintaining proper hygiene for her.

The above measures undertaken by the families of the individuals range from solely household-based to institutional care as well as folk remedies. Due to the families' socioeconomic status, faith healers are more accessible to them than psychiatric help. For Che's and Sheila's case, the first rehabilitative measure that they have undergone is through consulting a faith healer. This measure is urged by other people who deem the individuals as having been possessed, thus highlighting that the community and their views are major factors in the family's decision-making, next to their economic resources. However, both cases were unsuccessful in reversing the individuals' conditions, thus being forced to undergo the more economically-challenging strategy.

The individuals are all currently undergoing household-based rehabilitation due to their incapability to further seek professional help. Sheila's family have resorted to chaining her in order to shield her from the stigmatized reactions of people in the community as well as to prevent her from causing violence and harm unto others. The family has to work and provide for their own immediate families, thus prevents them from attending to Sheila's needs all the time. Therefore, they view chaining as the best alternative that could enable them to function throughout the day without constantly tending to Sheila, thus

their economic status also serves as a factor that determined what their rehabilitative measure for Sheila will be. Alma and Che are now tending to household chores and are also taking care of their niece and grandchildren. These household chores signify that since other people in their family are engaged in work, they must still perform household duties as a way of contributing to the family.

Providing socioeconomic support

The primary approach undertaken by the family members in coping with dementia is that they provide the older adult with socioeconomic support, through their food, shelter, medicines, and financial needs.

Both Nanay Milagrosa and Tatay Zosimo live in separate houses from their family members and primary caregiver, respectively. According to Mariel, this set-up is effective for them to avoid further conflicts within the household. She said: "*Kaya kailangan lagi na siyang nagso-solo eh. 'Yung walang makikita dapat na ano, na mga tao. Minsan man, okay siya. May panahon lang talaga na ano siya, laging mainit ang ulo."*

This information was also consolidated by one of their neighbors, saying:

> *"Sa pagkain hindi pinapabayaan pero never sila na nakita kong magkasama sa iisang bahay."*
>
> – Linabelle

In the case of Tatay Zosimo, he was provided by his granddaughter his own home since it has been a lifelong dream of his. Jennifer, one of his neighbors, said: *"Pinagawa niya talaga 'yan. Ginastusan niya talaga 'yan. [...] Pangarap kasi 'yan ni Tatay Simo eh. Kasi 'yung bahay nila dati kahoy lang."*

Despite their living arrangements, the older adults still continue to receive meals and financial support from their families as a way of sustaining their needs. One of Nanay Milagrosa's neighbors, Rita, said: *"Nakikita ko naman na nagdadala sila ng pagkain."* Lilibeth also adds: "*Sinusuportahan ng pagkain 'yan. [...] [Nagbibigay] ng puhunan, tapos si nana yang bibili [ng paninda]."*

Leonora states in behalf of Tatay Zosimo: "*Siya mismo nagbibigay ng konsumo, pangkain nila. [...] Tapos 'yung kuryente naman nila ang sumagot din dyan 'yung anak ni Cecil."*

"Pagpapabaya"

For the family members and primary caregivers, it is expected from them to sympathize with the demented older adults because they are the ones who are fully aware of their state and of their condition. This is one of the reasons why they are cautious of the repercussions that would arise from increased tension with the dementia patient.Mariel, the only daughter of Nanay Dapring, said: "'Pag pinatulan mo pa 'yan, magagalit na 'yan, magwawala na. Magmumura na 'yan. Kaya pinababayaan na lang namin. Alam na namin na ganun siya eh."

Similarly, Jane praised Amparo because of her patience and perseverance to fulfill her role as a daughter to her demented father, Tatay Salvador. During our interview, she said: "Bilib ako nga dito kay ano eh, kay Amparo, kasi ma-tiyaga talaga [...] Hindi siya 'yung umaangal na 'pag may sakit ang ama. Ginagawa niya talaga bilang anak."

STIGMA TOWARDS THE INDIVIDUALS AND THEIR FAMILIES

While Alma is able to hold conversations when she is in a positive mood, it is evident through Nanay Fely's and the neighbors' account that children, tease Alma for they know that doing this angers her. However, neighbors such as Jessica, Angeline, and Mameng tolerate Alma's short temperedness, all aware that objecting and retorting would only lead to further arguments. This shows that the neighbors are sensitive to Alma's condition, thus leading them to avoid as well as actively prevent Alma's outbursts.

While positive feedbacks have been obtained from neighbors of Sheila and Che, these contrast to the families' account. Sonia expresses her acceptance that not everyone can understand her mother's situation and that people will still continue to talk about them. Dolor expresses how her neighbors often say that they are a whole family of mentally unstable people. She says that this pains her to hear because others cannot understand what their family is going through. However, the three neighbors that were interviewed – Alona, Luz, and Elinda – all have positive things to say about their family. Luz expresses how she sympathizes with them and feels sorry for Sheila.

She also expresses that there are other people who also speak negatively of the family. Alona and Elinda also express this for they have witnessed how people would always

throw rocks at Sheila before.

Aside from possessing child-like characteristics, the most common symptom that the peers of the older adults with dementia observe are the evident changes in the former's mood and behavior. Some of the informants of the study claimed that the older adults would often initiate or worsen conflicts that eventually caused tension between them and their peers.

In the case of Linabelle, her relationship with Nanay Milagrosa (or Nanay Dapring, as they would call her) as neighbors ended because of the latter's attitude. She stated that: "Hindi na ako nakikipag-ano sa kanya, hinahayaan ko na lang siya. Wala na 'yung dati na lagi kaming nag-uusap. [...] Hindi ko na gusto 'yung ugali niya. [...] Parang na-consider ko siya na 'di ko na siya nakikita."

But contrary to the aforementioned case, there were still some informants who managed to maintain a bond with the older adult despite their change in attitude. Lilibeth, who is another neighbor of Nanay Dapring, said that: "Ang iba hindi nagustuhan ang sinasabi niya pero sabi ko, 'wag na lang pansinin kasi may edad na 'yan. [...] Pinagpapasensyahan na dapat 'yan."

CONCLUSION

The concepts and understanding of the locals of Baseco Compound on conditions such as schizophrenia and dementia commonly revolve around the symptoms attached to the said mental illnesses.

These concepts also reflect the severity of the individuals' conditions.

The family members and primary caregivers of the individuals resort to household-based approaches in coping with schizophrenia and dementia due to their insufficient knowledge on the aforementioned illnesses, along with their inaccessibility to proper and formal medical services. In addition to this, there is a greater show of importance on other physical conditions and complaints of the individuals (such as hypertension, arthritis, asthma, etc.) rather than their mental conditions; specifically that of their schizophrenia or dementia.

The changes in mood and behavior of the demented older adults mostly affected their

family members and neighbors, who also view dementia as a normal part of ageing and not as an illness per se. The community also harbors various views towards the individual, thus resulting in difficulties in their relationships. The community's views are also found to be significant factors in determining the specific household-based measure that they will undergo.

This study looked into the household-based approaches in coping with different mental illnesses, specifically that of schizophrenia dementia in Baseco Compound, Manila. Future research on other mental illnesses, such as depression, could be an attempt into understanding the importance of mental health in an urban informal settlement which lacks proper and complete medical facilities and services. In addition to this, a look into the gendered context of coping with mental illness could also be tackled in future discussions. Finally, policy implications on the effectiveness and implementation of the recently approved Mental Health Law are recommended. The reception of this law in different urban informal settlements in the country, and not limited to Baseco alone, should be observed.

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