Researching Institutional Elder Abuse in Malaysia: Challenges and Recommendations

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Despite a growing interest in elder abuse and neglect (EAN) among researchers and policy-makers in recent decades, most studies have concentrated on community-dwelling elders [1]. Little is known about mistreatment within institutional settings like nursing homes (NHs). This scarcity of evidence is especially palpable in low- and middle-income countries. Estimates from the National Center on Elder Abuse revealed that out of 44% of long-term care (LTC) residents who experienced abuse, only 7% of these cases were reported [2]. Compared to those living in the community, institutionalized older adults are at higher risks of abuse as they tend to be more physically dependent, have poorer cognition, lack social support, and come from lower socioeconomic background [3, 4]. Other factors have also been attributed to abuse in NHs such as inadequate staff training, lack of research, poor working conditions, funding issues, and absence of proper guidelines and screening tools [5]. In addition, gaps in policies and weak law enforcement – 2 common phenomena in low- and middle-income countries – often

translate into a “deficit” in regulation and monitoring of LTC facilities [6, 7]. This renders institutional abuse largely hidden and unreported.

In Malaysia, NHs and aged care facilities are either managed by the government (publicly funded), private entities, or nongovernmental organizations (NGOs)/welfare bodies. Public NHs and those run by NGOs are generally not for profit, while private aged facilities are mostly commercial. Each type caters to a distinct group; public NHs are mainly reserved for low socioeconomic elders who lack financial and family support and admission is strictly based on pre-determined criteria (e.g., partially dependent, free of communicable diseases, and lack of family support). NHs run by NGOs – also often meant for indigent elders – tend to target specific groups such as marginalized elders (e.g., refugees and HIV patients) or provide services based on certain affiliations such as faith (religion) or ethnic group. Private facilities, on the other hand, are costly, thus catering largely to the urban, higher income older populations [8, 9]. Currently, there are approximately twelve public NHs (9 in Peninsular Malaysia and 2 in East Malaysia) [10], 454 NGO-based NHs, and 1,019 private facilities [11]. However, according to unofficial estimates, the total number of NHs is 1,700, with 382

being registered. This discrepancy is due to a lack of reliable data and official websites not being regularly updated.

Systematic research into institutional abuse of older adults in Malaysia has been very limited. To this day, there has been no published data on the extent of the problem. The only published study is a survey by Nikmat et al. [12] in 4 public NHs that reported 13.6% residents having experienced some forms of abuse and neglect. However, the questionnaire items were not based on existing validated scales, and EAN was not the focus of the study. On the other hand, anecdotal evidence points not only to the existence of institutional abuse but its frequency. For instance, in September 2015, local newspapers reported that twelve people – including older adults and disabled individuals – were found locked up in an unregistered NH in squalid conditions [13]. Another media report emerged in October 2016 where a female NH resident was said to be physically assaulted by the facility owner [14]. A year later, a fire killed 4 elders in a nursing facility – a suspected incident of neglect [15] – while in a separate incident, a group of NH residents reported being hit, slapped, physically restrained, and overdosed with sleeping pills [16]. These alleged incidents suggested that institutional abuse could be more widespread than what is known.

Conducting studies among institutionalized elders in the Malaysian context has its set of challenges, which can be unique or similar to those in other countries or socio-cultural settings. Challenges can be categorized into methodological, administrative, individual, and cultural. Methodological challenges comprise 3 aspects. First, the diverse nature of NH facilities, in terms of management (government ministry or NGOs or private entities), targeted group (characteristics of residents), and availability of resources, poses a difficulty to researchers in ensuring a study sample that is representative of the entire institutionalized older population in the country. Existing studies have demonstrated the prevalent use of nonrepresentative samples among older adults, possibly indicating the complexities involved [17]. Second, a moderate proportion of NH residents are cognitively impaired – a phenomenon that often prompts researchers to exclude them, given the difficulty in assessment. However, empirical evidence shows that elders with cognitive impairment are more likely to be abused or neglected. It is thus plausible to assume that prevalence figures of EAN are underestimated. Third, identification of abuse perpetrators can be problematic as a result of the usual reluctance of elders to disclose information that can either cause

them embarrassment or punishment (retaliation) and the methods of assessment being not sensitive enough. Hutchison and Kroese in a prior review highlighted potential ethical issues that may arise due to the difficulty “to recruit and obtain consent from participants who could offer potentially valuable insight into substandard or abusive practices” [18].

Administrative challenges consist of 2 aspects. The first and most common is the bureaucratic procedures involved in obtaining permission and the lack of cooperation by some aged care facilities to allow studies in their premises. This can be due to either fear of disclosure of information that is deemed bad for the NH reputation or a sense of overprotection toward the residents by the management staff. Resistance against input from, and involvement of, outside professionals has been previously documented in research in institutional settings [19, 20]. Second, lack of transparency renders it difficult for researchers to access potential respondents (either residents or NH staff) and acquire accurate information about the adequacy of resources or manpower within the NHs. Existence of unregistered NHs – due to weak law enforcement – causes more complications; these facilities often escape regulatory oversight, thus putting residents at higher risks of abuse while being somewhat invisible or inaccessible to researchers.

Individual challenges refer to NH staff or residents or residents’ family members. Involvement of NH staff may be restricted by time constraint, high turnover rates, lack of interest, or fear of scrutiny. It was reported in a local study that the turnover rates in private NHs ranged between 18% among administrative to 39.5% among nursing staff [21]. On the other hand, involvement of residents tends to be impeded by cognitive impairment, lack of interest (due to little awareness on how research can benefit them), and ethical issues. It is not uncommon that residents’ family members are difficult to contact or visit rarely or refuse to participate; therefore, reaching out to them for research purposes can be taxing.

Cultural challenges are more subtle but can equally affect research endeavour in institutional settings. For instance, EAN is still largely considered a taboo subject in the Malaysian culture, given the strong tradition of filial piety (respect and care for elders). The practice of outsourcing care for older parents to aged care facilities like NHs, to a large extent, is regarded as inappropriate and frowned upon. There is stigma attached to this, which creates a tendency among elders to either deny experiences of abuse and neglect or refuse to disclose abuse perpetrators. Similarly, given the traditional norms of valu-

ing and looking up to elders, NH staff and family members might dismiss or avoid the subject of EAN. Another dimension of cultural challenge is that due to the lack of transparency and the practice of censoring information by authorities, freedom in acquiring, sharing, and publishing data can be restricted.

A number of recommendations are worth considering. To tackle the issue of sample representativeness, researchers need to carefully design the sampling strategy to avoid selection bias. A good approach is to conduct stratified random sampling, that is, to include all NH facilities (nationwide) in the sampling frame and randomly select a number of them, taking into account the weightage from each category (public, private, and NGO-based). Identification of EAN perpetrators can be improved if researchers or those involved in data collection are properly trained to ask sensitive questions. The questions, on the other hand, should be meticulously designed, culturally appropriate, and asked in environments that make respondents feel safe and protected. Owing to the multicultural and multireligious nature of Malaysian society, questions may need to be modified according to linguistic preferences, common terminologies used, and specific cultural interpretations of and attitudes toward EAN.

Administrative challenges can be addressed in 2 ways. First, benchmark setting or accreditation of aged care facilities can drive more NHs to open up, become more transparent, and encourage independent, external auditing and assessment. The culture of accreditation and greater transparency are expected to spur interest in research as NH management will see researchers as opportunities for feedback and improvement, instead of threats. A mechanism of providing incentives can be designed for NHs that comply to certain standards and criteria, such as funding or technical support by the government. Of equal importance is law enforcement to curb the mushrooming of unregistered NHs and gearing existing unregistered facilities toward formalization by adhering to strict standards.

Raising awareness and educating NH staff, residents, and their family members to recognize and understand the importance of research is crucial. This can be done through training sessions for NH staff and incorporating the subject (and discussion) of research as one of the components of residents' educational activities. What is more important is the normalization of research culture and the practice of testing a program and getting feedback that is aimed for older adults' well-being in the long run. Given the sensitive nature of EAN, a number of rules within NHs must be adopted such as protection of whistle

blowers or establishment of a complaint mechanism that ensures anonymity. Negative perception and attitude toward older adults, or known as ageism, ought to be tackled, especially when this exists among NH staff. Even though research on ageism in the Malaysian context is scarce, evidence from other countries shows that not only ageism is manifest in LTC settings but it also can lead to abuse by affecting the quality of services offered [22, 23].

Long and persistent efforts are needed to address cultural challenges standing in the way of institutional elder abuse research. First, taboos can be gradually debunked through the positive role of the media and public campaigns. The more EAN and institutional abuse are openly and honestly discussed in the TV, social media, and newspapers, the more society will "unlearn" old norms and embrace open dialogues about the issue. However, it is critical that public discussion on EAN is steered toward finding solutions and offering support to families in difficult situations, instead of giving emphasis on penalizing perpetrators or judging the practice of leaving older family members at NHs as a moral failure. Last but not least, unnecessary information censoring is generally due to lack of trust and effective communication among different stakeholders. Researchers can attempt to overcome this – or at least mitigate its impact – by building strong and genuine connections with stakeholders involved and making the research process more about exchanging feedback, and striving toward continuous improvement.

Last but not least, areas of research within institutional settings that need greater attention today include resident-to-resident aggression and prevention measures/interventions to address EAN [5, 24]. All in all, research is more readily facilitated when there is a win-win situation for all.

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