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Creators	Nasim, Sumaira, Lowe, Nicola M, Moran, Victoria Hall, Dillon, Stephanie, Zaman, Mukhtiar and Ul-Haq, Zia

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Original Article

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The Importance of Cultural and Socioeconomic Context in Health Research Design--- Lessons Learnt from a Pilot Study in Pakistan

Sumaira Nasim[a*], Nicola Mary Lowe[b], Victoria Hall Moran[c], Stephanie Dillon[d], Mukhtiar Zaman[e], Zia Ul-Haq[f]

[a]Assistant Professor, School of Public Health, Dow University of Health Sciences Karachi Pakistan.
[b]Professor, of Nutritional Sciences and Director of Research Centre for Global Development, UCLan, UK.
[c]Reader within the Maternal and Infant Nutrition and Nurture Unit (MAINN), UCLan, UK.
[d]Academic Team Leader In Sport, Exercise And Nutritional Sciences, UCLan, UK.
[e]Head Department of Pulmonology at Rehman Medical Institute, Pakistan.
[f]Vice-Chancellor/ Professor and Dean of the Faculty of Public Health & Social Sciences, Khyber Medical University Peshawar, Pakistan.
Correspondence: sumaira.nasim@duhs.edu.pk*

ABSTRACT

BACKGROUND & OBJECTIVE: For many health outcomes, there are an array of published methods; however, not all have been validated in the target population. So, it is better to first pilot the selected tools and research strategies, thus can reduce cost, effort and time in a larger project. The objective of this study was to present the significance of the pilot study by using an example of an observational study in a tertiary care hospital in Pakistan.

METHODOLOGY: This pilot study was carried out in a tertiary hospital located in Peshawar, Pakistan. The data (Socio-demographics, anthropometric measurements, biochemical tests, blood pressure measurement and diet intake) was collected from the un-paid female caregivers looking after hemodialysis-dependent family members. The caregiver experience was assessed using the Zarit burden interview (ZBI) scale. Pregnant and lactating caregivers were excluded.

RESULTS: Data were collected from 20 participants. The decision to participate in the study was based on male family members. Females were reluctant to provide anthropometric measurements and were not aware of monthly income. The majorities were interested in blood pressure measurement and blood tests as offered free of cost. Almost all participants reported positive aspects of caregiving. Thus, ZBI was not found suitable in the selected sample.

CONCLUSION: The results of the pilot study highlighted the strengths and limitations of the selected data collection tools. The results of the survey can be useful for the healthcare professionals involved in researching South Asian family caregivers.

KEYWORDS: Research, Culture, Caregivers, Pilot-project, Pakistan.

INTRODUCTION

One of the key decisions in the early stages of designing a research study is to determine the most appropriate methodology and methods for assessing the outcome measures within the target community and to assess the logistics of data collection within the given context. Searching the published literature for validated methods is a useful way to identify a range of options to assess the primary and secondary health outcomes, but not all published methods may be validated in, or are appropriate for, the particular cultural and socioeconomic setting of the proposed study. Undertaking a pilot study can be a useful way to refine data collection methods and can reduce the chances of failure of the research project in the main study [1]. To assure the feasibility of the proposed method, all the major steps of a main study can be executed in a pilot study with a small sample size. Moreover, the logistics of the study can be tested. A pilot study can also help to resolve conflict among research team members [2,3]. Moreover, this activity can increase the chances of securing funding for a full-scale trial as it can reduce the risk of failure of a proposed research project.

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This paper describes a pilot study that was undertaken to assess the methodological approach, data collection tools, participant recruitment strategy and logistics in preparation for a large-scale study to examine the impact of being a caregiver to a patient with chronic disease on the caregiver's health and wellbeing.

Previous research has indicated that taking on the role of caregiver can have a negative impact on the mental and physical health of the caregiver. The caregiver burden of those supporting patients living with kidney diseases is particularly high [4,5]. As dialysis is the usual treatment for patients with chronic kidney diseases (CKD) and is performed two to three times per week, it requires frequent hospital visits. Such patients often face multiple co-morbidities and require more dietary modifications and fluid restriction compared to other chronic diseases. All these factors lead to a high level of dependency placed on family members as caregivers.

Previous research in this field has been conducted primarily in developed countries[5,6]. For instance, Tong et al. conducted a systematic review and meta-ethnography of 16 studies that evaluated the effectiveness of interventions aimed at providing support to caregivers of people with CKD, all of which are conducted in HICs. The analysis revealed that the carers reported a high burden of fatigue, uncertainty, and limited socialization[6]. Similar findings are reported by Gilbertson et al. in a systematic review of 61 quantitative studies investigating the quality of life and burden to caregivers[6]. The authors highlighted the wide variability in the tools used to assess the impact of caregiving, and it was unclear whether the tools had been validated for use in the particular populations and cultures under study. The tools used to measure the impact of caregiving and indices of health are often developed within the cultural and socioeconomic context of the study and may not be transferable to other contexts and cultures. Therefore, the primary aim of this pilot study was to assess the suitability of established tools to assess the health of caregivers within a low-resource setting in Pakistan.

METHODOLOGY

Context and inclusion criteria:

The pilot study took place at a Lady Reading tertiary care hospital (LRH) in Peshawar located in the capital of Khyber Pakhtunkhwa, Pakistan, which is the largest and oldest public-sector teaching hospital and most of the services are provided free of cost. The inclusion criterion were: unpaid female adult caregivers; providing care for more than six months; providing care to an adult dialysis-dependent family member; and must assist in at least any three of the following Activities of Daily Living (ADLs): personal hygiene, dressing, preparing food and feeding and getting in and out of bed. One of the phlebotomists who work at the dialysis unit offered his services to recruit study participants to assist as most of the caregivers were comfortable communicating with him.

Data Collection Tools

1. Socio-economic status (SES):

SES is an important determinant of health, and various tools have been developed to assess SES. The Kuppuswamy scale is the most widely used in South Asia and is often modified according to the aims of the particular study [7]. In our study, as men in Pakistan are usually the head of the family and responsible for household income, we included information regarding the education level and occupation of the head of the family as well as the study participant. We also replaced the occupation and education closed response items with open-ended questions to make them more relevant in this study setting (Table-I).

a. Anthropometric measurements

To assess the risk of chronic disease, the following anthropometric measurements were chosen:

Weight: was measured in Kilogram (kg) using a validated weighing scale up to one decimal place. The recommended method to measure weight is in light clothing, without socks and shoes.

Height: was measured using a stadiometer in centimeters (cm) up to one decimal place. Three readings were obtained, and the average was calculated and recorded.

Body Mass Index (BMI): BMI was calculated using weight and height measurements, and participants were classified as normal (18.5–<23kg/m2), overweight (BMI 23–< 27.5kg/m2) and obese (BMI >27.5kg/m2) using WHO criteria for South Asians.

Waist and hip circumference: According to the WHO criteria, the preferred method is to collect directly on the skin using a non-stretchable tape. Nevertheless, an alternative option is for the participant to wear light clothing, which was the option chosen as it was considered more suitable within the cultural context of Pakistan.

a. Biochemical tests

Blood glucose levels, triglycerides and cholesterol are reported as useful biochemical markers to assess the nutritional status and risk of chronic diseases. Dialysis is a daycare procedure. Therefore, the length of stay in the hospital is usually limited, making tests requiring fasting not possible. To overcome this limitation, a random blood sample was collected, and biochemical analysis was conducted using a PRIMA device which requires a single drop of blood to measure blood lipid profiles. The instrument provides a result within five minutes. Using the National Cholesterol Education Program Adult Treatment Panel-3 guidelines, participants were categorized as either no-risk, moderate risk or high-risk categories for chronic disease (Table-II).

a. Clinical assessment:

Raised blood pressure can increase the risk of chronic diseases such as diabetes, CKD and heart disease. Thus, blood was measured using a sphygmomanometer and stethoscope and participants were asked to sit quietly for 15 minutes with their legs uncrossed[9].

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[1] (Antonio Monti 7 CH - 6828 Balerna Switzerland)

Table-I: Modification in Kuppuswamy Scale.

Kuppuswamy Scale was updated in 2012 [8]	Modified for this study
1. Education Professional degree or honours Graduate or Postgraduate Intermediate or post-high school diploma High School Certificate Middle School Certificate Primary School Certificate Illiterate	1.Education Education of head of family: Your Education: years Age upon reaching highest qualification: years Highest qualification: ears
2. Occupation Profession Semi-Profession Clerical, shop-owner, farmer Skilled Worker Semi-skilled worker Unskilled worker Unemployed	2.Occupation Occupation of the head of the family: Your occupation:
Monthly income (in Pakistani Rupees): >32050 16020-32049 12020-16019 8010-12019 4810-8009 1601-4809 < 1600	3.Monthly income of the head of the family: (in Pakistani Rupees): Your income: PKR Family income: PKR

Table-II: Risk of chronic disease on the basis of chosen biochemical test.

Biochemical test	No risk	Moderate risk	High risk
Total cholesterol (mg/dl)	Less than 200	200-239	Greater than 240
Triglycerides (mg/dl)	Less than 150	150-199	200-499
Random blood sugar (mg/dl)	79-160	160-200	Greater than 200

d. Dietary intake

Participants were asked to describe their dietary history, which was recorded by a dietician (SN). This was considered more representative of the participants diet than a more quantitative 24-hour recall method since caregivers were in a hospital setting, and it was assumed that their diet intake would be affected by this and, therefore, not a true representation of their routine intake.

D. Exercise and physical activity

Patients visiting LRH usually belong to the Low-Income group, where women usually stay at home and do not participate in planned walks or exercise activities. Thus, Physical activity was estimated by asking questions related to the length of time taken for routine household activities in a typical 24-hour day.

E. Caregiver burden

A 22-item Zarit Burden Interview (ZBI) tool was used to assess caregiver burden, which has been used in a variety of cultural settings. Questions are designed to assess the subjective burden of caregivers, which makes it possible to assess the caregiver's health, psychological wellbeing, money matters and socialization. Participants indicate their responses on a Likert scale from 0 to 5, where 0 indicates never, and 5 represents nearly always. A high score represents a high burden [10].

Ethical considerations

Ethical approval was obtained from the University of Central Lancashire STEMH Ethics Committee (Reference number: STEMH 693). A consent form, a participation information sheet (PIS), a questionnaire and all data collection tools were translated into Urdu (the national language of Pakistan). All the procedures followed were in accordance with the Helsinki Declaration.

RESULTS & DISCUSSION

Participant recruitment and obtaining consent:

Most of the women contacted requested that permission should be obtained from the male member of the family who had accompanied them. This might be attributed to limited literacy, lack of understanding of research and the meaning of consent, and/or the role of men in decision-making. This trend is found in other LMICs [11].

It was difficult to identify the primary caregiver by the inclusion criteria as 77% (n=13) were living in a joint family system, and ADL was performed by different family members living with the care recipient. This may be positive in that it reduces the burden and any sense of isolation that the role may induce. Each family member can act as caregiver in the joint family setup, and therefore, the individual effort and time commitment to caregiving can be relatively small.

Socio-economic status and demographics:

Most of the participants were unemployed and held no formal education. 54% of women were not aware of the family income. However, if the husband or any male member of the family accompanied the participant, he provided this information.

Recording the age of the participants was also a challenge, as many did not know their date or year of birth. The question frequently precipitated conversations amongst the family members to try to gain a consensus on the age of the respondent. As age is often used as a trigger for screening of certain diseases, misreporting of age may lead to unnecessary or delayed screening tests (such as screening mammography). Misreporting of age may also lead to decreased study power to detect differences between age groups. Thus, results may not be generalizable. As the majority of the respondents did not know their ages, the researcher asked if she could record this information from their national identity cards[3].

The researcher also explored the question of age by trying to link the participant's date of birth to key religious or cultural events or any major change in life. One participant commented, "My mother told me that I was born when there was the first war between India and Pakistan", which translated to a date of birth in 1965. This approach for estimating age in LMICs was also reported by Haandrikman, as the authors acknowledged that retrospective data collection in LMICs can be challenging and prone to recall bias. Thus, the use of tools such as a time-path calendar for local events and festivals can be helpful in gathering correct information.

Table-III: Observations and suggestions for a research study on a related topic.

Pilot study objectives	Tools/strategies employed	Observations and challenges	Suggestions for improving the methodology
Obtaining consent	Consent form translated into Urdu.	Participants were reluctant to give consent and sought permission from their husbands or male member of the family.	Involve family members and hospital staff with whom patients are familiar, and develop rapport.
Participant Information Sheet:	PIS form translated into Urdu	Lack of understanding of research activities	Involvement of family members and hospital staff can be a useful strategy.
Assessment of SES			
1. Age	Using Interviewer-administered Questionnaire	Most of the participants did not know their date of birth	Ask for National Identity Card Probe for date of birth related to any religious or cultural event or any major change in life.
2. Income	Using Interviewer-administered Questionnaire	Female participants were not familiar with the household income	Involve family members, and gather information regarding ownership of assets such as a house, vehicle or monthly utility bills.
Anthropometrics 1. Weight 2. Height 3. Waist and Hip Circumference	Weight, height and waist circumference was measured as part of the nutrition assessment.	Most of the participants agreed to weight and height measurements but refused the removal of the veil. All refused waist and hip measurements.	Separate room for anthropometric measurements to ensure the privacy of the study participants.
Biochemical	Benchtop rapid blood analysis for RBS, TG and cholesterol	Some participants refused due to fear of results indicative of a health issue	Include healthcare professionals from the same institute, explain the benefits of biochemical tests and possible treatment/ management in case a potential health issue is indicated.
Diet assessment	24-hour diet recall questionnaire	This tool is not ideal for assessing individual nutrient intake; however, it can be used to estimate diet diversity.	If detailed nutrient intake data are required, multiple diet assessment methods can be employed, also including the use of weighed-food records, food models or pictures to estimate portion size and the use of mobile phone technology[4].
Physical activity assessment	Questionnaire to assess daily household activities.	Due to joint family system, household activities were shared, thus difficult to assess.	Use of technology such as wrist worn Accelerometers
Caregiver burden assessment	Used ZBI tool	This tool does not capture the positive aspects of the caregiving role.	Use of culturally appropriate questionnaires which can capture both positive and negative aspects of caregiving.

Anthropometric measurements:

Weight: As almost all the participants were covered with a Burqa or chador (as a veil), weight was measured in heavy clothing, which led to an overestimation of their weight. The researcher requested that participants removed their veils, but due to the presence of male staff in the data collection setting, female participants were reluctant. This can be mitigated by arranging separate rooms where the privacy of the participants can be ensured.

Height: Socks and shoes were removed upon request. However, as all the females had their heads covered, height measurement may have been overestimated. None of the participants refused to provide height measurements.

Waist-hip ratio: All participants refused to provide waist and hip measurements. This refusal was mainly due to the lack of availability of a separate room where privacy for the female participants could be ensured, as they removed outer clothing or lifted their clothing to enable these measurements to be made. This limitation is reported by Sicotte et al., who undertook a study in Mali, West Africa [12]. The nutritional assessment was obtained on the basis of anthropometrical data. Sicotte reported that due to cultural reasons, waist and hip circumferences were difficult to measure. Thus, when choosing an appropriate anthropometric assessment tool, considering cultural context is important.

Biochemical tests:

Biochemical tests were relatively easy as the majority of the participants were highly motivated by receiving the test results. Participants whose results placed them in at-risk categories were advised to visit a qualified doctor for further investigations. However, some dietary advice was provided by the first author, who is a registered dietician in Pakistan.

Clinical assessment: Nearly all participants gave consent

[4] *In LMICs, use of mobile phone is nearly 90%*

for blood pressure measurements to take place. This may be because they were aware of the link between raised blood pressure and kidney disease, as exhibited in the people they care for. Caregivers can become more health conscious and more likely to adopt a healthy lifestyle to prevent or minimize their risk of chronic diseases.

Diet assessment:

The information was gathered regarding eating habits and types of foods consumed by the participants. Paratha/roti with a cup of tea was frequently reported for breakfast, while vegetable or lentil curry with roti/chapatti was often reported for lunch and dinner. The researcher tried to probe further regarding the consumption of other food groups, such as fruits and milk, but these foods were viewed to be a luxury and non-affordable. It is common practice in Pakistan, especially in low SES groups and in rural areas, for family members to share the curry plate and chapatti. It was difficult, therefore, to assess how much curry and chapatti were consumed individually.

Physical Activity:

The majority of the participants were living in a joint family system, where household responsibilities and taking care of dependent family members was shared. It was difficult, therefore, to assess how much physical activity was carried out by one person and how physical activity varied on a daily basis. Most of the respondents mentioned that after adopting the caregiver role, their physical activity levels fell due to time spent sitting next to the patient. Similar findings are reported by Secinti et al., who undertook a study to compare the health behaviours of caregivers with non-caregivers. In this study, over a third (35%) of the caregivers reported weight gain, and 42% reported increased physical activity after embarking on this role. Thus, the caregiving role can lead to an increase or decrease in physical activity.

Caregiver Burden:

ZBI for assessing caregiver burden did not yield useful data in our study cohort. Due to the low level of literacy, participants found it difficult to understand the scale, and when the researcher attempted to probe, many participants seemed annoyed and were reluctant to engage. For example, when a mother as a caregiver was asked, "Do you feel that you will be unable to take care of your relative much longer?" she replied angrily, "No, she is my daughter. I will take care of her".

Yujin Kim shared her experiences identified in a pilot study conducted to collect qualitative data from Korean-American caregivers of dementia patients [13]. She acknowledged that sometimes researchers put effort into finding the responses they are looking for from participants. For instance, as the main objective of this pilot study was to assess caregiver burden, the researcher expected more responses relating to the expected burden, particularly in this low-resource setting. However, it was surprising that despite the limited resources, caregivers were determined to take care of their dialysis-dependant family members and often took pride in this role.

CONCLUSION

This pilot study revealed that many positive aspects of being a caregiver were raised by the participants that were not captured in the ZBI score, which focused primarily on the limitations imposed by the caregiving role. Thus, a tool that explored both positive and negative aspects of the caregiving role was identified for the main study.

This study demonstrated that while conducting research in LMICs, the use of the tools and strategies developed in HIC should be first piloted to ensure their suitability. This pilot study provided valuable information to mitigate the risks associated with collecting data in the proposed setting, specifically in terms of the choice of tools used for the key outcome measures. Some suggestions for conducting research in a similar context are summarized in table-III, which might be useful for both researchers and healthcare professionals.

The study also revealed that researchers should consider the perspectives of study participants and their cultural and religious values when formulating research questions and deciding on appropriate data collection tools. Caregivers described a number of positive aspects of the caregiver role and were surprised to consider the role of the caregiver as a burden, as described in the ZBI tool. This experience suggests that using tools to assess both positive and negative aspects of the caregiver role can provide more meaningful data.

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[a] *portable card issued by Government of Pakistan, contain information regarding age, gender, permanent address.*

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Author's Contribution:

Sumaira Nasim: Conceived the idea, collected and analyzed the data and wrote first draft of the paper.

Nicola Mary Lowe: Refined the study protocol and manuscript writing.

Victoria Hall Moran: Refined the study protocol and manuscript writing

Stephanie Dillon: Refined the study protocol and manuscript writing

Mukhtiar Zaman: Refined the study protocol, assisted to arrange logistics for data collection and manuscript writing.

Zia Ul-Haq: Refined the study protocol, assisted to arrange logistics for data collection and manuscript writing.

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