

# Recruitment of elderly patients for research and data collection – experiences with a Hong Kong Chinese sample

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**Abstract** Recruiting elderly people for studies is a challenge for researchers. This paper discusses experiences and insights into recruitment of elderly Chinese participants for a restraint reduction clinical trial. Areas addressed include obtaining informed consent; factors affecting data collection; involvement of ward staff and relatives; and clinical research personal attributes. Insights suggest research personnel must appreciate and attend to cultural differences. Giving written consent is a serious matter for Chinese elderly; thorough and repeated explanation, plus family involvement is crucial to subject recruitment and retention. Researchers must recognize values, beliefs and perceptions, and external and internal factors that might distract elderly subjects during recruitment and data collection. Older Chinese patients are often accommodating and tend not to voice concerns despite doubts or when not well enough to continue an interview or assessment. Ward staff involvement is also recommended at each stage to bridge communication between patients, their relatives and the research team.

## INTRODUCTION

Findings from studies inform us that the use of physical restraints does not reduce falls or injuries (Capezuti *et al.*, 1998; Dunn, 2001; Evans *et al.*, 2002; Shorr *et al.*, 2002). To investigate the effects of a restraint reduction programme, our project team conducted a prospective clinical trial in two rehabilitation settings, one serving as the intervention site and the other as the control site. The intervention consisted of a staff education programme and the setting up of a restraint reduction committee (RRC). The study was a collaborative project between the School of Nursing and two rehabilitation hospitals that commenced in May 2002. All medical and rehabilitation patients admitted to the study sites were potential participants. Each day at the ward, the research assistant (RA) identified all new admissions from the ward's daily record. He then introduced himself to the new patients and sought their consent to take part in the study. In the pre-intervention phase, 528 subjects with a mean age of 75.4 (Standard deviation [SD]=10.8) were recruited. Although the majority of

the subjects did not drop out of the study, the rate of successful recruitment was only 41.4 %.

The recruitment of older persons for research has been identified as a complex process, the difficulty of which should not be underestimated by researchers (Harris & Dyson, 2001). Few papers have discussed the recruitment of elderly subjects from different racial groups. This paper reports our experiences of recruiting elderly Chinese patients as subjects, as well as retaining them during data collection processes. Methods to optimize response rates during recruitment and to assure successful data collection will also be discussed. These measures are also important in minimizing the risk of missing or incomplete data.

### Building Up Rapport

Before approaching patients, it is essential to learn some details about them, such as the reason for admission. The research assistant should first focus on the patient's chief complaint. It is helpful to start the dialogue by talking about the patient's main concern. For example, for a patient admitted for chest infection,

we could ask, "Is your shortness of breath better today?" or for a patient suffering from stroke, "Do you feel that you are gradually regaining strength in your arms and legs?" Developing a person-to-person relationship helps a patient to feel that he or she is being valued as an individual, not merely somebody to be examined. This is essential for developing relationships with elderly Chinese patients as the older generations of Chinese are more reserved than the younger generations of Hong Kong Chinese, as they have been influenced by an educational system modelled after Western ideology. Nevertheless, elderly patients are willing to talk about their discomforts and concerns once they have warmed to a person. Therefore, being a good listener helps to develop the initial trust required for further interactions.

It is also possible to build up a rapport between research personnel and elderly subjects through other means, provided the interaction of these means does not confound the study's results. The concept and processes of research are often alien to older Chinese patients. To keep the recruited subjects better informed about the research they were engaged in, various means were adopted in our study to provide them with a clearer picture of what participation in research entailed. Other modes of communication, such as the discussion of health education pamphlets, the provision of educational seminars, and talks about hospital caregiving by the staff for patients, their relatives and friends were all part of our intervention programme at the intervention site. Other than building up relationships with the subjects to retain them as participants in the study, these interactions shed new light on how patients and families think about issues related to the use of physical restraints, and enabled the research team to target actions that were more likely to resolve their concerns.

### **Appreciating "Cultural" Differences**

Naranjo and Dirksen (1998) maintained that cultural values and beliefs should be appreciated as they might strongly influence recruitment. Any research team should appreciate cultural differences between elderly subjects and researchers, as they may increase the possibility of mistrust (Daunt, 2003). It would be incorrect to think that all Chinese are similar in cultural background, and therefore should interact without problems. Although Hong Kong is a homogeneous society with 95% of its population

Chinese in origin (Census and Statistics Department, the Hong Kong Government, 2003), the consideration of cultural differences between research personnel and subjects still warrants our attention. This applies to studies in any Asian country, or for that matter any country. China is a vast country and has countless dialects, usually classified into seven main groups (Yuen, 1960). In addition, Hong Kong has a history of being a place of refuge for people from different parts of China during the world wars and the civil war, as well as in the post-war era.

Language is the first issue that needs to be considered. Although Cantonese is the most popular Chinese dialect in Hong Kong and one of its official languages, a significant number of elderly subjects speak in their own dialects, for example, the Fukien, Shanghai, or Hakka dialects. An attempt to communicate with elderly patients in their own dialect is recognition that their mother tongue is an important part of their being, and is certainly appreciated. It is easier for a researcher to break the cultural barrier if he or she can speak those dialects or at least some simple sentences in those dialects.

Another area of note is whether research personnel are sensitive to the traditional values and religious beliefs of the elderly. Traditional Chinese philosophies and religious beliefs serve as the underpinnings for the conceptual basis of health, disease and interpersonal relationships (Gaw, 1993). The major philosophies influencing Chinese patients' values, beliefs and perceptions of health include Taoism, Buddhism and Confucianism. Some Chinese patients believing in Taoism may ascribe their illness to bad luck; Buddhists may exhibit stoic tolerance of the pain resulting from their illness because it might be perceived as a positive that could lead to future rewards; and to those who practice Confucianism, illness is due to antagonism with fate and therefore they have to accept fate's guidance (Shih, 1996). In order to establish a trusting relationship and facilitate communication with subjects, a researcher should be culturally sensitive to traditional Chinese religious beliefs and philosophies. This is essential because health care professionals and research personnel are often members of a younger generation, which more often than not does not share the same traditional values and beliefs as the older generation. Learning about subjects' beliefs and practices is helpful in communicating with

them, especially when they are staying in an alien environment such as a hospital ward. Research personnel must be sensitive to the beliefs of elderly Chinese and avoid being unknowingly offensive.

### Clarifying the Roles of Research Personnel

Shih (1996) pointed out that most Chinese patients value health caregivers' support and opinions highly. Many have observed that Chinese people with traditional values seem to be more obedient to authority and authoritative figures. Jang (1995) observed that Chinese people readily adopt the sick role and become dependent and passive. Adherence to a formal dress code by research personnel can sometimes be useful, because it may get the attention of potential subjects. Wearing a white coat can therefore help to break barriers. To date, the white coat seems to be identified as a symbol of the helping professions. Therefore, potential elderly subjects may be more willing to participate in a study when they are approached by a member of staff in formal attire than when a stranger in casual attire approaches them (Neumark *et al.*, 2001).

Sometimes, a researcher in a white coat is mistaken for a medical doctor. Some patients might even ask research personnel for permission to be discharged. It is important, and only ethical, to explain the research personnel's role in the ward so that subjects do not hold misconceptions of the role the research team and what they can do for the subjects. During a brief encounter, a first impression is always crucial, regardless of what the person is wearing. A smile from the researcher will go a long way in getting off to a good start. This, however, probably applies across different cultures.

### About Written Consent

Researchers should be aware that impaired vision, hearing and cognitive function are some of the barriers in recruiting elderly subjects. Among these barriers, the cognitive impairment of subjects is a primary obstacle (Bowsher *et al.*, 1993). Using coloured paper, appropriate lighting, corrective lenses, hearing aids, large print, written instructions, and conducting interviews or assessments in a quiet place may eliminate some of the barriers and facilitate communication. For subjects who are cognitively impaired, their families

or proxies need to be approached for proxy consent. However, it is not only those who are incompetent to give consent that might need to have their families approached. Harris and Dyson (2001) point out that whenever there is doubt about whether an elderly person can fully understand the study, their relatives' assent needs to be sought in order to ensure full protection of the rights of the elderly subject.

Detailed explanations of the study and respect for the subjects' rights are essential. Obtaining informed consent acknowledges the subject's right to autonomy, dignity, and self-determination (O' Hara *et al.*, 2003). However, getting written consent from elderly Chinese can pose a major problem. In practice, it is not easy to determine which elderly subjects are unable to fully appreciate the study and need to have their families involved. Findings from overseas studies inform us that most elderly people in advanced countries have completed a high school education. Yet the mean number of years of education for elderly Chinese is two (e.g., Lai, 2003). The vast majority of older Chinese had no opportunity for formal education, and many of them are illiterate. In situations where a higher level of demand is placed on an individual's power of comprehension and judgment – such as the novel situation of joining a research study undertaken by a young and modern-looking health care team, plus having to sign a document to indicate agreement, can be stressful and alien to older people. In our experience, some elderly Chinese patients were apprehensive, and some probably fearful of the term "research". Further discussions revealed that some linked "research" with some kind of medical or surgical procedure. As farfetched as it may seem, some subjects also associated giving consent with agreeing to an "autopsy" of the subject's own body should they unfortunately pass away. Our Chinese elderly patients were especially scared when asked to sign the consent forms, and would anxiously ask about any possible consequences or outcomes. To some of our older subjects, the act of signing a consent form was associated with important decision-making like the acceptance of some particular intervention or surgery. Therefore in terms of recruitment, careful and repeated explanation of what is involved in consenting to participate in a particular study is crucial.

## Factors Affecting the Data Collection Processes

Once the patients have agreed to participate in the study, the research personnel can collect data by interviewing the person, performing required assessments, or reviewing medical records. It is essential to ensure the optimal comfort of subjects during interviews and assessments, as this enhances the possibility of success in obtaining the necessary data. The following factors, both internal and external to the subjects, need to be considered.

External factors include the environment, noise, people around the patient, and the schedule of ward activities. Interviewing subjects in a noisy, busy, crowded ward obviously is much less effective than in relaxing, peaceful, and quiet surroundings. A day in the hospital means a busy schedule for the patient in a rehabilitation setting. Sometimes, the recruitment or data collection processes are interrupted by various activities or procedures – visits by occupational, physical, and speech therapists, grand-rounds by the consultant, and personal or nursing care procedures. It is pertinent that research personnel have an awareness and understanding that allows them to compromise with the health care team on when they are able to have access to the subjects. Other strategies include avoiding particular periods and being flexible with the work schedule of research personnel.

Internal factors that may affect the data collection processes include the subjects' own worries about their health, distractions by visitors, postural comfort due to treatment or treatment-related factors, the level of pain if present, and so on. Sometimes, subjects might feel anxious because they do not know how to answer the researcher's questions. At other times, their emotions are triggered by particular interview questions, especially when they are asked about their diseases or disabilities, or about the availability of family support and their social network. We also found that some elderly subjects might easily lose their concentration during interviews if they are waiting for their relatives or friends to show up. Hence, research personnel need both good planning skills to determine the right time to conduct an interview, and flexibility to cope with sudden changes that can happen at a moment's notice.

In general, Chinese people can be described as rather protective of their young and their old. Similar to

Bowsher and associates' (1993) experience, we found that while relatives and friends can provide support during an interview, they can also become concerned and interfere with the processes, thinking that their elderly relatives are being used in research, and that the questions being asked are too personal. It is therefore pertinent to enlist families' understanding and support through adequate communication.

Fluency, accuracy and efficiency in the use of instruments can facilitate the process of data collection. Research personnel with professional knowledge can facilitate the data collection process since they are familiar with not just the instruments, but also some basic medical and health information. Occasionally, research personnel might be asked questions about medical conditions or diseases, and the ability to provide brief answers is very comforting to the patients.

Research personnel should be attuned to subjects' need for comfort by frequently observing their gestures and facial expressions. This is a salient point to remember when working with older Chinese subjects. The Chinese are known to be more accommodating in nature, especially those of the older generation who were brought up in a culture that emphasized etiquette and manners. They may not immediately tell research personnel how they are feeling, even if they do not feel well enough to continue. Researchers should pay attention to the time commitment made by the elderly subject on each occasion. Prior to the beginning of the interview, a mutually agreed time to end the interview should be set, and that time should not be lengthened indefinitely, even though elderly subjects are usually more obliging. In our study, we noticed that many elderly patients could not tolerate assessments or interviews that lasted more than twenty minutes. It is worth taking this into consideration during the study design stage. Related assessment items or procedures can be sectioned into chunks so that the subjects will be capable of coping with the demands of a multi-dimensional assessment. The research personnel should have the skills to redirect dialogue with the subject back onto the right track if irrelevant content is brought up/introduced by the subjects. Once the subjects warm up to the research assistant, older Chinese patients, who might not have a lot of people talking to them throughout a day in the hospital, might start telling the researcher many other things

about their lives. Being focused on the questions will improve the efficiency of the data collection processes.

### Involvement of Ward Staff and Relatives

Support from ward staff can ease both the recruitment and data collection processes. Ward staff can act as a bridge for communication between patients, their relatives and the research team. They have the advantages of being trusted figures in the unit, more familiar with patients' likes and dislikes, and also of knowing the patients' families. Often, messages that come from the staff will be much more convincing to the families. It is therefore advisable to keep all ward staff informed about the progress of the study. We found that good communication and understanding between the research team members and the hospital's managerial staff was the key to smooth recruitment and data collection. Chinese people value the maintenance of harmonious relationships within groups and communities. Such collegial relationships need to be cultivated, especially when there is no previous relationship between the researchers and the agency (Neumark *et al.*, 2001).

Resnick *et al.* (2003) state that lack of support from staff or relatives is a major challenge and barrier to research. O'Hara *et al.* (2003) propose several strategies to promote staff participation for successful research in long-term-care settings. These include promoting a sense of project ownership by staff, consideration of their opinions, and operationalizing staff suggestions into concrete actions. Over time, mutual understanding and trust will develop between the staff and the research team concerning each other's roles. Collaterals, the persons in some way involved in the care of the elderly and providing assistance in their activities of daily living (for example, maids or personal assistants sent to the hospital by families), are important too (O'Hara *et al.*, 2003). They have a part to play in helping the elderly with memory or functional impairments, as many subjects may be unable to communicate with the researcher. Having worked with an elderly person for a long period of time, they would have a better understanding of what the subjects need and how they fare on certain assessment items.

### Attributes of the Clinical Research Personnel

Nishimura *et al.* (2003) state that research assistants are the key to coordinated data collection through effective communication with subjects, principal investigators and any other persons in contact with subjects during the research process. Clinical research personnel who collect data from elderly subjects in clinical settings should have particular attributes. They should be able to work independently, identify the problems and difficulties encountered, and provide practical solutions by reflecting on actual ward conditions. They need to have the flexibility and knowledge to know what elements can be adjusted in the processes, bearing in mind the objectives of the study as well as the uses and possible misuses of the research instruments. Upon receiving any comments or complaints about aspects of the study from patients, their families or ward staff, the research personnel should have the interpersonal and communication skills to discuss, clarify, and negotiate how best to resolve certain issues with them without compromising the quality of the study.

### CONCLUSION

It is often a challenge for researchers to recruit elderly subjects for studies. Giving written consent is a very serious matter for elderly Chinese. As stated earlier, the idea of conducting research is alien to many older Chinese. Local data informs us that 42.4% of those aged 65 and above have had no schooling, 39.1% of them have had a primary education, and only 18.4% of them attained a secondary education and above (Census and Statistics Department, 2003). The research personnel have an obligation to ensure that older Chinese patients and their families fully understand what they are committing themselves to when giving their consent. This is essential for elderly Chinese, as traditionally speaking their high regard for those in authority might oblige them to participate because someone they regard as an authoritative figure has asked them to do so. Thus, it is also essential for research personnel to clarify their roles – that of being a researcher and not a member of the health care team.

Because of the low literacy level of the older Chinese population, it is crucial for researchers to employ various methods, for example - formal and informal

discussions, sharing and brief group sessions - to explain to potential subjects the matters being studied as well as the procedures involved. Not only is it our moral responsibility to do so as researchers, but also it helps to continually engage elderly Chinese subjects in the research process.

Older Chinese may ascribe a special meaning to their illness and suffering. Research personnel must be able to appreciate and attend to cultural differences between elderly people and themselves. Coming from vastly different backgrounds, care should be taken not to belittle the cultural and religious beliefs of the older Chinese, albeit unknowingly. Other than recognizing the major philosophies influencing Chinese patients' values, beliefs and perceptions of health, research personnel should be attuned to both personal (such as pain) and environmental factors (for instance, noise) that might distract elderly subjects during the recruitment and data collection processes. Lastly, the pivotal part played by ward staff should not be under-estimated. When involved in each stage of the study, staff can act as a bridge for communication between patients, their relatives and the research team.

Changes in clinical practice underscore the need for nursing research in Hong Kong (Mackenzie, 2001). Conducting quality, cost-effective clinical studies can help service providers to realize the best clinical practices in service settings (Chang *et al.*, 2003). Appreciating the characteristics of hospitalized elderly Chinese patients is fundamental to successful recruitment and data collection. Responsive recruitment and valid data collection processes that are attuned to the special characteristics and needs of older Chinese patients are integral parts of a high quality study.

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### 招募年老患者参与研究和搜集数据——从香港华人样本中所得的经验

招募长者参与研究对研究员来说是一项挑战。本文通过一项在两所复康机构进行有关减少约束物的临床研究，探讨招募华人长者参与研究的经验及从中所获得的启发。研究人员必须能够认识和处理自己与长者之间所存在的文化差异。由于研究人员有时会被视为医护团队的一分子，因此厘清研究人员角色是很重要的，此举可避免他们作出超出其角色范畴的工作。对华人长者来说，他们视签署参与研究的同意书为非常重大的事情，所以，研究人员务须充分及反覆向当事人解释详情，以及让其家属参与其中，这才有助招募及确保有关长者一直参与整个研究过程。此外，华人长者的价值观、信念和对健康的看法必须得到重视。研究人员在招募和搜集数据过程中，亦应调适各项可能分散长者注意力的内外因素，例如噪音等外在因素和痛楚等内在因素。华人年老患者通常十分顺服，即使在受访或接受评估时中感到疑惑或感到不适难以继续下去时，仍不会即时作出表示。至于病房职员，他们在研究的每一阶段均应参与，以担当病人、家属和研究队之间的沟通桥梁角色。招募反应热烈，以及有效的搜集数据过程，均对提高研究质量大有帮助。