RESEARCH NURSES AT THE FRONTLINE OF INNOVATION IN CLINICAL RESEARCH.

Clinical research is diverse. But all kinds of clinical research are done to find answers and after finding answers, publications are done to help facilitate researchers in the future who will have similar questions about a particular subject. As we try revolving around to find answers, we involve the most crucial aspects of clinical research, the subjects. Clinical research involving human subjects is the most evidence-based research. Regardless of the fact that we may not know the cure to a disease like ‘nodding disease’, the nurse must give up on the wellbeing of the patient or more importantly, the betterment of the patients’ life.

Even as we concentrate on clinical research, we cannot overlook the value of human kind. It is the role of the nurse to hold the research subjects as a priority and scrutinize them for safety measures as the whole health care team works together to find answers to particular research questions. But what does it mean to be at the frontline of patient care during research? What responsibility does it bring to a nurse? It takes more than seeking consent from a patient, observing anticipated signs or routine patient management. It takes the power of critical thinking. It requires highly rated innovation skills. Research questions on a particular disease can never be exhausted even when answers are found. Answers yield more questions. However, for diseases with a lot of question marks to their pathophysiology, questions are to infinity. It is challenging to effectively manage a patient without knowing the pathophysiology of the condition he or she has. As many have researched on the causes of nodding disease, several different causes have been assumed. Some teams suspect that the disease is related to exposure to a chemical released during the LRA (Lord Resistance Army) war in northern Uganda while others believe the disease is transmitted by a parasitic worm, Onchocerca volvulus that is common in all areas with the nodding disease syndrome. My team has looked for answers too in Kitgum, northern Uganda. What are the effects of the disease but most importantly, what challenges have the natives experienced having seen this disease manifest amongst them for four years and what have they resorted to as special management for their patients. A nurse cannot afford to miss the difficulties faced in the management of nodding disease and the circumstances that led to the loss of the research subjects in this research. Most of the victims of nodding disease die of starvation not because of lack of food but the lack of ability of the patients to eat as they start nodding when familiar foods are presented to them to eat. Others wonder off to fires or steams when they get seizures. Infact, a large percentage of the victims who are affected first by the disease were lost in this manner. As the team collects data, a nurse also focuses on patient management. How best can the health care team protect the victims of nodding disease during research? If emphasis was put on provision of unfamiliar foods that can stimulate good brain development may be the loss of nodding disease victims would be less than the reported number currently. That stills brings more and more questions to this research. The ways in which nodding disease victims can be saved from starvation and mental retardation are in question? Much as seizure medication has proved to be of great help, starvation is still a challenge in nodding disease victims. However, I believe this is not the first disease in the world that puts its victims at risk of malnutrition thus clinical interventions can be discovered. That still opens for more research on nursing care in nodding disease syndrome. Necessary restraints would make much, a difference too. That way, care
takers would be able to take care of the patient as they carry out their income earning activities like farming without worrying that their patients will wonder off to dangerous places during seizure attacks.

Critical thinking towards innovation may not be pre-planned because not everything we come across during research is anticipated. However, nurses should have an open mind so as to critically think of effective measures on how to manage and protect the research subject. One may wonder why we should do the best we can to protect patients and prioritize quality of life. It is to value life even when the treatment of a disease of a kind like nodding disease is not known. Secondly, protection of patients that have been affected by a vague disease is key so as to know the long term effects of the disease and how they can be managed. A particular research team may not benefit much from this action of protection but a research team in the future will definitely benefit from this by taking documented innovation suggestions into consideration as they carry out their research so as to achieve more precise results. This is why ‘research’ (re-means before, search-means to find) is called so. It’s because one searches for something that has been done before but with a more specific goal and with better methods that will yield answers to more specific questions than the research done before.

A nurse should work with the rest of the multi-disciplinary health care team in this vital duty of protection of research subjects. The nurse has the responsibility to make certain that the team holds protection of the research subject as a first priority in all steps of the research. This plays a critical role for better research in the future. Much as the cause of nodding disease has not been found, I believe the publication of our work together with suggested innovations for patient management and protection during the research on the disease will be of great merit to future researchers in order to find the better answers as regards to ‘nodding disease’.