

Second Mini grant Presentation

Use and Efficacy of Peer Support and Social Networking in Diabetes Management in Kenya and Uganda by Dr Habil Otanga, University of Nairobi

Questions and Comments Section

Question: Was the research for both male and female? Again, is it female and male or female alone because the quotations I heard were from the female gender or was it that the females speak out more than the men.

Response: This research was for both men and women but I have only used two quotes from this female respondent but in the qualitative paper of course we have the quotations for everybody else.

Response: I met a very interesting participant I wish she would have met her too. She actually wanted to speak more even beyond the allocated time and I think by the virtue of her age she was 74 but she normally prefers being referred to as under 14. I think by the virtue of her age she has seen a little bit more she's able to relate to issues at levels that people at a lower age might not be able to. So, this female was just a beautiful resource.

Question: Thank you Habil for that very provoking presentation. It is very interesting and what caught my attention a bit was the choice of the study setting especially in Kenya and I was just wondering what informed that consideration in view of the fact that we find the prevalence of these non-communicable diseases to be a bit higher in the central high lands of Kenya and perhaps other areas, just maybe you can give us an insight of that and also now thinking about the area in relation to how far we can be able to generalize your findings to other settings in Kenya and perhaps Uganda. The other thing which caught my attention and which got me thinking is the issue about stigma and this is just a comment I was thinking that perhaps what we are seeing is that this peer support and social networks appear to be facility centred and almost being driven by the health care providers rather than emanating from the community and therefore am thinking myself and perhaps this is something that can intrigue the study that there is need for communities sensitization on NCDs where people are not saying that you are getting diabetes because you are rich and eating a lot of sugar. I think the study now should be maybe going into future also into our research activities looking at the issues of community sensitization

as another way of preventing NCDs so we will be reducing stigma as well as improving adherence for diabetes patients. Then my other question is just a clarification you said that the test for diabetes I think cost 180 dollars in Kenya shillings that would be around 23000 is that the correct figure maybe I missed something. Thank you so much.

Response: Thanks for your kind comments. I will start with your comment on stigma and I agree with you entirely we need education for the masses to understand what diabetes is and how it comes about. On clarification sorry it is 18 dollars not 180 dollars I think I was thinking more about money. And then the choice of location. I said initially that I fear hospitals just like I did when I was 2 years old and so we did not conceive this study from the medical practitioner's point of view we considered this study from the social scientist's point of view to try and understand in places that are poor, people who are poor to what extent are they able to take care of NCD not in terms of where is the highest prevalence of NCD. We just sampled areas that we thought poverty levels are high and so we wanted to have an understanding of the how does that poverty intersect with the management of NCDs.

Question: Thank you Dr Otanga for your work. I have a couple of comments and a question. First of all, I am a cardiovascular physician, and so half of my patients are diabetic I see them every day in hospital I don't blame you for fearing hospitals even doctors do fear hospitals sometimes. One thing we probably need to appreciate from the work that you have done is to identify what happens beyond the hospitals. In hospitals we diagnose diabetes we put patients on treatment and then the burden of what goes wrong happens beyond the time they leave hospital. Two issues you have raised one of them was adherence to medication still remains a big challenge to us. The second one is just general follow up and being able to link these patients to healthcare facilities and I am very impressed by identifying some of the social networks and also utilizing community health volunteer workers to be able to follow up these patients. This is one of the big tasks that we have in cardiovascular care especially in diabetes to try and do what we call task sharing and task shifting trying to identify people skilled and nonskilled to be able to equip them with skills to help us follow up our patients with good care. As you might be aware from the cardiovascular side diabetes, hypertension are two very common conditions almost three quarter of our patients with diabetes have hypertension and many of them after about 12 or

15 years with poor control would end up having chronic kidney disease and some of the patients you see on dialysis and of course that has major economic implications to families and the society. Let me come to my 2 questions. First of all the test you talked about that is hbA1c in diabetes medicine we normally call it the big torch that helps us to see in the darkness of diabetes which means that it helps us to see exactly what happens within 3 months of our patient in terms of sugar control care. It is still expensive ksh.1800 is not very cheap to people living in urban areas to even country side. So the question is if you had the resources today and you are asked to advise health leaders in our region what single intervention would you advise them to invest their money in to improve our diabetes care. Before you answer the question because I won't get another chance to speak regrettably I see you have a challenge in getting money to publish your good work I know your grant was a one-time grant but we are open we can write to the centre and see how best we can be able to get your work published. Thank you very much.

Response: Thanks Dr Bukachi for educating me. I will also thank you for the opportunity to write to the centre. Trust me I don't have a silver bullet now, what I can do if I had the resources is that one thing is to advise policy makers to improve diabetic care. I would request that you just give me a few minutes to think about it.

Question: Mine is an observation may be not a question as such but first to really thank sincerely Dr Otanga and the team for the good work that they have done I think this is really great. Now the one thing that I had hoped to really hear about is in relation to price of medicine is the opportunity cost and given that this is a large condition what I have observed is that diabetic and other NCD patients often look for drugs where they can get the cheapest price but my thinking often is that even if they do so there is often other opportunity cost of looking for this cheap medication first in terms of transport in terms of time what would be your comment on this in the context of poverty. Then in some situations we find that more than one household member is diabetic or has other NCD what does this mean in this kind of family setting where we have more than 1 person really taking this medication and as you mentioned the issue of the burden of disease so to me this is just an observation and of course I just hope that the question by Dr Bukachi doesn't just end up in this meeting but perhaps we see another write up on this as well. Thank you.

Response: I associate entirely with your sentiments especially the intersecting role of poverty and diabetes management and I still want to go back to the quote from my participant in Mariakani that diabetes does something to someone and then that person stops working and then because they stop working then they are not able to take care of themselves then the diabetes gets worse. In the same case someone has to go very far to look for drugs or even just to attend diabetes management in a public health care facility it also means therefore that they cannot even do anything else because of that time spent or distance. As I said initially access is a big issue and because of that therefore people might as well be spending more time looking for medication attending hospital than taking care of themselves. By itself it makes them a burden to others. Now when a family member is sick I said initially the whole family is sick. More money is expended on this person not only on their diet but also on their drugs, the drugs that they use. Taking care of them becomes a problem because we also have opportunistic infections that they get like sores on their feet that is also something they need to take care of so initially it was diabetes but now we have sores like Dr Bukachi said we have hypertension and the rest. So I think just my opinion that a family member with diabetes is actually the entire family with diabetes because they are not able to live their lives normally sometimes at the expense of their economic livelihoods. Thank you.

Question: Of course, when we talk of diabetes as an NCD we find that this kind of disease when it comes to support especially from the donors the extent of support tends to slim compared to a communicable disease and this is because of the effect it has on others which is not the case with diabetes for example. So how can we now change this insistence of assistance by the donors in terms of the NCDs so that we can have a lot of help just as we have help with the communicable diseases because we have seen a lot of discrimination when it comes to how say diabetes in terms of assistance, we get so is there a way that we can try to come up with a way of reducing that discrimination. Thank you.

Response: I think that way starts now by awareness. When people are aware that it is a problem then it becomes a problem. As you said there is so much discrimination between communicable and noncommunicable diseases through management and funding why because researchers in

communicable diseases made it a problem because it actually is but by doing so we forgot noncommunicable diseases. And maybe it is just that time to have data because that data is also not very appropriate so we need data to convince the world that this is a problem then we can start financing that problem. Thank you.