

# Literacy and Diabetes (Diabetracy)

Apologies for not being here- (Ofsted are our lord and master)

Diabetes and Literacy- where is the link?

Understanding literacy- What type of literacy

Linking perceptions of literacy and health

Existing information- Impact of poor health literacy

What next- Towards Diabetracy- family/school level and sufferer level

Goals of literacy in the context of diabetes- Management and prevention

Conclusion





# Apologies



- ▶ I had genuinely looked forward to this event for months. Unfortunately, my department got a call that Ofsted would be inspecting us from between Monday (today and Wednesday). As the Network Coordinator, I have to be with any of our Partner colleges being inspected by Ofsted- Hence my absence. I look forward to meeting you at other for a in the future
- ▶ Dr Gordon O. Ade-Ojo, Faculty of Education and Health, University of Greenwich



# Diabetes and literacy

- ▶ Am I qualified to talk about diabetes? Maybe yes, maybe no. I only had a C in biology and that was many decades ago.
- ▶ Am I qualified to talk about health literacy? Again, maybe yes, maybe no. I am very educated with two Doctorates and four Masters degrees. But does this make me health literate? My answer is NO!
- ▶ The above is the basis of my argument for the importance of what we might generally call health literacy, but in this particular context, diabetracy- Literacy for managing and preventing diabetes.
- ▶ Before setting out my case, please read the scenario in the next slide and discuss with your colleagues. The key question is; does the case study present an argument for the recognition of the importance of literacy in health? How and why? Is this applicable to diabetes? Do you think the scenario might be replicated with some diabetes patients?



# A case study

- ▶ He came in for a “tune-up.” He was 64 years old, with a “history of noncompliance,” according to the resident, and he hadn't taken his diabetes or cardiac medications for weeks. We weren't quite sure why. He was alert, he appeared to be intelligent and interested in getting well, and he was able to get his prescriptions filled at a reduced cost. Before he went home, we explained why he needed to take his medicines and reviewed the frequency and doses with him several times. He told us he would follow up with his doctor (though he couldn't remember the doctor's name or telephone number) and left the hospital with a handwritten discharge summary. Five months later, he appeared at the community clinic. He said he was taking his medications, but he wasn't sure of their names or how often he took them. A medical student and I reviewed the regimen again. The student typed up simple instructions in big letters for him to follow, as well as a list of dates and times at which he should record his blood sugar levels. We asked him to come back in two weeks. When he returned, the student saw him first — and made a diagnosis that no one else had considered: illiteracy. The clue lay in the jumbled mess of his glucose log. Many of the sugar values were written next to future dates. We quietly asked him to read his list of medications aloud. Haltingly, he told us he couldn't do it. Born in the rural South, he had left school in the second grade. He lived alone. He had been able to support himself as a gas-station attendant and handyman, but he had never learned to read. We were stunned. We had tried to avoid jargon and to use simple language in explaining our instructions, and he had seemed to understand everything we had told him. He had seen scores of doctors, nurses, and social workers over the years without anyone's guessing he had a reading problem. Although we had been blind to his illiteracy, our patient's problem is not uncommon
- ▶ Some preliminary conclusions: (a) literacy is relevant for our health (b) being aware of issues around health is not a substitute for being literate in the area of health



# Understanding literacy

- ▶ What really is literacy?
- ▶ Most dominant view of literacy is that it is simply the cognitive engagement with reading and writing. In reality, literacy goes beyond the dominant form of reading and writing.
- ▶ Illustration (myself): I am officially classified as highly literate, yet I cannot use the instructions provided by IKEA to put together a simple table. Am I literate in DIY? The answer is no!!!
- ▶ Literacy can be seen as a social practice (Street, 1984, 2006, Barton and Hamilton, 2000) with each practice having different events and represented by different forms of literacy
- ▶ Hence, literacy does not come in one form but can be specific to different practices (Ade-Ojo, 2014). So, although we might be literate in one practice, we might not be literate in others. Being able to read and write does not necessarily mean that we are health literate.
- ▶ Let us look at the set of information provided in the next two slides and discuss the implication for health literacy.



# Literate but not health literate: the HIV/Aids problem in Africa

- ▶ While Zimbabwe and South Africa have some of the highest literacy rates in Africa, they are also the countries most severely challenged by HIV/AIDS.
- ▶ It is estimated that in Zimbabwe, up to 25% of the population is infected, the majority of them women (UNAIDS/WHO, 1999). UNICEF's recent Progress of Nations Report 2000 highlights that there is a disproportionately high incidence of HIV/AIDS among sub-Saharan African teachers (UNICEF, 2000).
- ▶ In 1999, at least 860 000 elementary students in sub-Saharan Africa lost a teacher to HIV/AIDS. The rate was particularly high in Kenya, where ~1400 teachers died in 1999, affecting some 95 000 primary students (compared to only 10 teachers in 1993). Consider the 1999 data for other African countries: in South Africa 100 000 students lost a teacher to HIV/AIDS, in Zimbabwe it was 86 000, and in Nigeria 85 000.
- ▶ The high death rate of teachers shows clearly that general literacy and health literacy do not necessarily go hand in hand. It illustrates that literacy and health literacy are moving targets and must be viewed in context. In this context, literacy is the totality of practice and not just awareness. Our goal must be to develop literacy as a social practice around health. This might include how we get others to behave and how others get us to behave in relation to health

# I can read, but can I practice? A case for health literacy

Look at the diagram below. If we removed the instruction numbered 1 to five on the left panel, would it mean anything to you in terms of your health?

**1 Start Here** →

**2 Check Calories**

**3 Limit these Nutrients**

**4 Get Enough of these Nutrients**

**5 Footnote**

**6 Quick Guide to % DV**

**Quick Guide to % DV**

- 5% or less is Low
- 20% or more is High

**Nutrition Facts**  
Serving Size 1 cup (228g)  
Servings Per Container 2

**Amount Per Serving**  
**Calories 250**      **Calories from Fat 110**

	<b>% Daily Value*</b>
<b>Total Fat</b> 12g	<b>18%</b>
Saturated Fat 3g	<b>15%</b>
Trans Fat 3g	
<b>Cholesterol</b> 30mg	<b>10%</b>
<b>Sodium</b> 470mg	<b>20%</b>
<b>Total Carbohydrate</b> 31g	<b>10%</b>
Dietary Fiber 0g	<b>0%</b>
Sugars 5g	
<b>Protein</b> 5g	
Vitamin A	<b>4%</b>
Vitamin C	<b>2%</b>
Calcium	<b>20%</b>
Iron	<b>4%</b>

\* Percent Daily Values are based on a 2,000 calorie diet. Your Daily Values may be higher or lower depending on your calorie needs.

	Calories: 2,000	2,500
Total Fat	Less than 65g	80g
Sat Fat	Less than 20g	25g
Cholesterol	Less than 300mg	300mg
Sodium	Less than 2,400mg	2,400mg
Total Carbohydrate	300g	375g
Dietary Fiber	25g	30g

# Health literacy: what is it then?

- ▶ Several definitions in the literature, but we can draw a central conclusion from all of them.
- ▶ “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health” (World Health Organisation, 1998, p. 10)
- ▶ a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment” (American Medical Association Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999, p. 553)
- ▶ “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 32)
- ▶ Health Literacy is the ability to read, understand, and act on health care information(Center for Health Care Strategies Inc., 2000)
- ▶ Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health(Nutbeam, 1998)
- ▶ Some observations:
  - ▶ A. All the definitions suggest that health literacy goes beyond merely reading health literature
  - ▶ B. We can argue for the empowerment of the citizenry through health literacy definitions as above(Freire, 1985; Freire and Macedo, 1987) and address the concern over the poor health literacy levels of large numbers of patients in the American health care system (Parker et al., 1995; Pfizer 1998; Parker, 2000)
  - ▶ C. Overall, we must recognise that health attracts a particular type of literacy and that literacy goes beyond merely reading and writing.

# Impact of poor health literacy

- ▶ Three key areas in which poor health literacy might impact of the community. These are all hinged to the notion of using literacy as a tool for obtaining information and using the information to engage in a particular practice
- ▶ Obtaining relevant information: Where and how do patients and potential patients get information relevant to the illness? This requires a particular level of literacy and without it, such a simple task becomes onerous. Raises the issue of trust between sources of information and user of information. If the potential user does not associate with the practice of the particular literacy involved, they are unlikely to trust the source (Might be nurses or other health practitioners)
- ▶ Processing and understanding the information available: For anyone to be able to practice a particular literacy, they must be able to engage with the meaning-making processes involved with such a literacy. If people are unable to process the relevant information relating to health practice, they are unlikely to be able to engage in the practice (Refer to the label we saw earlier on. Anyone who could not process the label will not be guided by it)
- ▶ Using the information: Poor health literacy means that people are unable to use available information in order to engage in meaning-making and therefore making it a part of their practice. This raises issues around the need for a culturally relevant form of literacy. Meaning making cannot be achieved if the content/information is not culturally relevant.



# What next: Towards Diabetracy

- ▶ Health literacy is important, but for us not sufficient.
- ▶ We argue that literacies ought to be designed around the major debilitating illnesses in our society. Abundant evidence that when literacy is designed specifically for a vocation/discipline people interested in that vocation are likely to become more engaged. (See for example, Ade-Ojo, 2014 on literacy for NEETS (Not in Employment Education and Training), Duckworth 2014 on transformative literacy and Duckworth and Ade-Ojo, 2016 on transformation through literacy)
- ▶ On this basis, we argue that there is a need to develop a specific literacy for diabetes and similar illnesses. Hence we could have Diabetracy.
- ▶ Diabetracy would be a specific literacy practice that promotes the management and prevention of diabetes
- ▶ Diabetracy would be useful for health practitioners, children adults and people suffering from diabetes and others at risk of suffering from diabetes
- ▶ Developing diabetracy will enable people literate in this literacy form to engage in its practice and therefore prevent and manage diabetes



# Target and form of delivery of diabetracy

- ▶ Form: Must be built as a distinct literacy
- ▶ Located in school curriculum: children learn the practice early and become involved in prevention. They can also help with management and prevention for adults in their family
- ▶ Located in the curriculum of healthcare practitioners: As practitioners, they can become a conduit for management and prevention while managing other illnesses. There is evidence that diabetes is often developed with and as a result of other illnesses.
- ▶ Target: Entire society in general but specific focus at this point on children, people with diabetes, people with the potential for developing diabetes and healthcare practitioners including care givers.
- ▶ Discussion: Discussion on how we could develop a template for diabetracy: content etc Any chance of developing a project that could pilot it and measure the impact? (Health trusts, schools, literacy specialists and healthcare practitioners)



# Goals of Diabetracy

- ▶ Two central goals must be:
  - ▶ Prevention
  - ▶ Management
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# Conclusion

- ▶ Every practice has its own literacy form
  - ▶ Same is true for health and particular health issues can be better managed if sufferers and potential sufferers are engaged in practice through literacy
  - ▶ It is viable to apply this principle to the management of diabetes and similar diseases.
  - ▶ We call for the development of diabetracy which should be made available to young people through specific literacies in schools.
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