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# **Developing a health link partnership with dermatology services in Nigeria: Preliminary feedback from a Tropical Health Education Trust start-up project**

*Andrew R Thompson & Nicholas Taylor*

*In January 2013 we visited Nigeria to build a partnership with Nigerian dermatology-services and a dermatology charity. The needs assessment that was conducted supported a DCLinPsy doctoral study. This article reports on the initial phase of the start-up project and presents some of the results of the needs assessment.*

## **Nigeria**

Nigeria is the largest country in West Africa consisting of 250 ethnic groups. It has a population of over 155,000,000 people giving it the highest number of citizens on the African continent (Central Intelligence Agency, 2011). The country has over 200 spoken languages with the official language being English.

Mental health care in Nigeria is known to face challenges and support for psychological issues associated with long-term health conditions is very limited. There are generally fewer mental health facilities than in Western countries and the first line of support as elsewhere in West Africa is typically from within local communities, often in the form of religious or traditional healer intervention (Ayonrinde, Gureje, & Lawal, 2004).

## **Background to the Sheffield-Lagos health link**

In early 2011 Ogo Maduewesi, Founder/Executive Director of the Vitiligo<sup>1</sup> Support and Awareness Foundation (VITSAF) contacted the University of Sheffield in connection with a DCLinPsy study that had been supervised by Dr Thompson, Reader in Clinical Psychology. This

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<sup>1</sup> Vitiligo is an unpredictable and typically long-term condition that results in the loss of the skins protective pigment and consequently leaves noticeable white patches on hair and skin. The condition is not curable.

study had examined the effectiveness of using augmented cognitive behavioural self-help in reducing social anxiety associated with this visible skin condition (Shah et al., in press). The self-help materials used had come to the attention of VITSAF who were interested in examining the potential for using such interventions in West Africa.

Stigmatisation associated with vitiligo is known to be particularly problematic in Nigeria partly because of lay confusion of the condition with leprosy (George, 1989). Stigmatisation connected with the condition is also not uncommonly reported in the UK (Thompson et al., 2002; 2010) where the development of self-help for people living with dermatological conditions is also needed (All Party Parliamentary Group on Skin, 2013; Lavda et al., 2012). The high level of stigmatisation coupled with the lack of services available in Nigeria and also to a lesser extent in the UK, suggested that the development of self-help might be a particularly useful context in which to build an international health link partnership.

A potential collaboration gradually emerged over several months of email and Skype communication between Ogo Maduewesi and Dr Thompson. Dr Thompson was initially invited to present at an innovative ‘stakeholder conference’ that was being organized by VITSAF, which included international delegates with expertise in the medical management of vitiligo. As one of VITSAF’s central aims is raise awareness of the condition, a plan was also discussed of conducting a small-scale needs assessment of Nigerian’s experience of living with vitiligo during the conference visit. As such a project was a potentially appropriate DCLinPsy study it was consequently advertised to Sheffield trainees, and Nicholas Taylor expressed an interest in undertaking this work.

VITSAF worked hard to secure funding for the stakeholder event, however unfortunately, due to difficulties securing funding the conference was cancelled twice. The event eventually took place in October 2012 but with less financial support from sponsors than had been anticipated. Although some international delegates were able to attend there was insufficient funding for everyone to attend and consequently Dr Thompson presented electronically (see

<http://www.youtube.com/watch?v=CKHPicUtvU0>). VITSAF used the conference to raise awareness of the treatment needs of people living with vitiligo and disseminated the output across a number of different media (website, youtube, facebook, newspaper, and printed booklet).

VITSAF's inspirational work inspired us to seek to develop a wider link with Nigeria, and Dr Thompson sought to extend the emerging relationship to include a formal partnership with Nigerian healthcare professionals. Guidance and funding to support this work came in the form of the International Health Links Framework, where a 'link' is described as a "formalized voluntary partnership between counterpart health organisations in the UK and a Developing Country (DC). The primary purpose of Links is to build the capacity of the DC organization, but there are also important secondary benefits for the UK health sector" (Tropical Health and Education Trust: THET, 2009, p.15). The THET model is designed to "start small but aim high" (p.99) and so this naturally fitted the scope and stage of the proposed project.

VITSAF introduced Dr Thompson to Professor George, an Honorary Consultant Physician and Dermatologist. Professor George and Dr Thompson then collaborated on making a successful application for an International health links start-up grant, provided by the Tropical Health and Education Trust (THET), funded by the UK Department for International Development. Gaining support for this partnership involved seeking advice and practical support from a range of individuals with experience of working in West Africa (see acknowledgements). In particular, practical support was provided by the University of Sheffield's West Africa Regional Officer, who was able to provide local support in setting up the link in Lagos.

### **The initial visit**

The start-up grant funded Dr Thompson and Nicholas Taylor to visit Lagos for seven days in January 2013 to meet with key stakeholders including the secretary of the Nigerian Association of Dermatologists, and other clinicians (psychiatrist, psychologist, dermatologists, and nurses) working in a number of healthcare services in Lagos. The funding also enabled a preliminary needs

assessment to be conducted, and supported the running of a workshop for people living with vitiligo in the community (run in collaboration with VITSAF in the outskirts of Lagos). The visit thus served as an opportunity to conduct further assessment of the UK developed self-help materials and to explore the materials acceptability and utility within a Nigerian context. The visit provided an essential opportunity to examine the cultural acceptability of the existing self-help materials and to ascertain if it was worth conducting further development and testing of its effectiveness in Nigeria.

Finally, the visit provided an opportunity to support VITSAF in raising the profile of vitiligo via participation in local media activity. However, the primary aim of the start-up grant was to establish a formal partnership and develop a memorandum of understanding relating to the delivery of psychological support to people living with long-term skin conditions in both the UK and Nigeria.

### **The needs assessment**

The first part of the needs assessment conducted during the visit was a qualitative exploration of the psychosocial issues associated with living with vitiligo. The aims and methods mirrored studies previously conducted in the UK (Thompson et al., 2002; 2011). The second part of the needs assessment was focussed around examining the usability of a self-help leaflet developed in the UK (Shah et al., in press).

#### *Design*

The methods used were scientifically reviewed and ethical approval was gained from the University of Sheffield. In addition, mechanisms for ensuring appropriate cultural sensitivity were built into the protocol. In conducting research or needs assessments where cross-cultural issues are present it is important to strive for a participatory approach so that the impact of difference can be understood and where possible taken into account in the design, analysis, and interpretation of findings (Gunaratnam, 2003).

Interpretative Phenomenological Analysis was used for the first part of the needs assessment and eight participants were interviewed about their experience of living with vitiligo. Nicholas Taylor conducted the interviews in collaboration with Ogo Maduewesi and the findings from one of the participants will be briefly described below. A Think Aloud (TA) interview schedule was also used with participants following the semi-structured interviews to explore the usability and cultural appropriateness of a psychosocial self-help leaflet (Haak, Jong, & Schellens, 2003).

### **Results from the analysis of one of the participant's**

The results from one participant have been selected for discussion here as they demonstrate how resilience can develop following the initial impact of the condition.

Thomas (pseudonym) is a sixty-two year old man, who first noticed the white patches characteristic of vitiligo following a visit to hospital for a routine injection when he was aged 31. Here he describes his initial reaction, in much the same way as other people have done in studies from elsewhere in the world (e.g. Borimnejad et al., 2006; Thompson et al., 2002; 2010). He described his first reaction as being one of confusion and concern about the change in his appearance and that this was coupled with frustration as he attempted and failed to gain treatment.

*“Well I went to the hospitals, I went to the local teaching hospital here where they gave me some funny injections....not even medical doctors knew what the name was...they didn't”*

Thomas explained that in parallel to his own concern his family was also worried, particularly as they misattributed the condition to be leprosy.

*“...my elder brother actually took me to a leprosy clinic...it was then I realised that they actually thought what I had was contagious”*

In addition to people mislabeling the condition and consequently fearing contamination Thomas described people as holding a range of causative illness perceptions associated with traditional belief systems, typically perceiving the vitiligo to have been caused by bad spirits, which in turn tends to be viewed as a punishment for straying from traditional customs.

*“Some people say something that I did is wrong. Some people say that I’ve done something against traditional custom. Some people even say that I’ve eaten something that I was not supposed to eat, and some people even say, “Don’t eat crayfish, don’t eat this,” and all that. They all attach it to some form of spiritual thing”*

Thomas gave numerous examples of experiencing ongoing episodes of discrimination and intrusive reactions.

*“I would go to the market, women would not collect money from me”*

During his early years of living with the vitiligo Thomas described becoming extremely self-conscious, sensitive to humiliation, and mourning the loss of his former appearance which he had valued highly.

*“I was self-conscious, I was allergic to people looking at me. I could quarrel with anybody if you looked at me for long. I used to have a very nice face and then suddenly when that went, initially I was fighting against it...I could have committed suicide because of it”*

Thomas described the important supportive role played by experiencing a sense of acceptance from his wife, children, family, friends, and colleagues. He also talked about the importance of his Christian faith.

*“I mean if I hadn’t God’s grace I don’t think I would have coped”*

Over time Thomas described having developed a range of responses so as to manage both his own and the negative reactions and the inquisitiveness of strangers.

*“And at the end of the day they say, “What happened to you?” and I’ll tell them, “It’s natural, it’s vitiligo, it’s a loss of pigmentation, and it can happen to anybody.”*

Thomas described having grown through the experience, demonstrating a sense of pride in his ability to live with vitiligo and seeing it as something that he had had bestowed upon him and must learn to live with.

*“Yes, it’s a positive thing today but initially it was negative. It was destructive then”*

*“I am not doing anything to change this. I wouldn’t really want to go back to being completely black”*

This truncated excerpt from the individual analysis of Thomas’s interview demonstrates the similarities between living with an appearance altering condition across the world – concern with loss, lack of access to healthcare support, the reality of experiencing intrusive reactions, and the importance of the pre-existing value placed on appearance in one’s self concept (Thompson, 2012). His excerpt also demonstrates the importance of learning skills to actively manage the intrusive reactions of others. Finally, it gives a unique insight into the broader role of cultural beliefs and traditions in illness perceptions that must be understood in developing any form of intervention.



## Future plans

We are currently seeking further funding to develop the partnership. We plan to take the collaboration forward in several ways. The first aim will be to promote the findings from the needs assessment so as to support the work of VITSAF. In addition, we plan to conduct further research to develop accessible psychological interventions.

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