Social Science & Medicine 161 (2016) 27–36

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study

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ARTICLE INFO

Article history:
Received 15 February 2016
Received in revised form
17 May 2016
Accepted 18 May 2016
Available online 20 May 2016

Keywords:
Chronic illness
Depression
Disability rights
Mixed methods
Nigeria
Stigma
Sickle cell

ABSTRACT

Sickle cell disorders (SCD) and depression are both chronic illnesses of global significance. Past research on SCD and depression struggles to make sense of statistical associations, essentializes depression within the person with SCD, and treats stigma as an automatic correlate of chronic illness. A mixed methods study (March 2012–April 2014) was undertaken with people living with SCD and depression in Lagos, Nigeria, examining *depression-as disease* (questionnaires); *depression-as-illness-experience* (individual depth interviews), and *depression-as-societal-sickness* (focus groups). 103 people with SCD attending an outpatients clinic were administered the *Patient Health Questionnaire-9*, and 82 self-identified with some level of depression. Fifteen were subsequently interviewed about their illness experience. Their lives were characterized by being extensively subjected to vicious discriminatory remarks, including from significant others, negative experiences they felt contributed to their depression and even to suicidal thoughts and actions. Contrary to misconceptions of the relational nature of stigma, respondents recognized that stigma resulted not from their SCD but from assumed broken social norms and expectations, norms to do with educability, employability and parenthood. They recounted either that they successfully met such expectations in their own lives, or that they could conceivably do so with reasonable societal adjustments. Ten respondents with SCD and depression further took part in two series of three focus groups with five people in each series of groups. In groups people living with SCD were able to challenge negative assumptions about themselves; to begin to recognize collective social interests as a group, and to rehearse backstage, in discussions between themselves, social actions that they might engage in frontstage, out in wider society, to challenge discriminatory societal arrangements they held to contribute to their depression. To the extent that depression in SCD has social origins, then social interventions, such as anti-discrimination laws and policies, are key resources in improving mental health.

1. Introduction

Sickle cell disorder (SCD) is a chronic illness of global public health importance (UN, 2008). Up to 330,000 infants are born globally each year, and this figure is expected to increase to over 400,000 by 2050 (Piel et al., 2013). SCD has been recognized as a public health priority by the World Health Organization in Africa (WHO, 2010). Globally, Nigeria has the greatest absolute number of people with SCD, with up to 150,000 infants with SCD born each year (WHO, 2006). Depression is a major chronic illness globally in its own right, and is described as a major contributor to global health burdens (Moussavi et al., 2007). Numerous studies have documented an association between SCD and depression (Ohaeri et al., 1995; Hasan et al., 2003; Asnani et al., 2010). However, since pain is itself highly, and reciprocally, related to symptoms of depression (Kroenke et al., 2011) and since both acute vaso-occlusive painful crises and chronic pain are integral to the experience of living with SCD (Smith et al., 2008), it is unremarkable that people with SCD should also be prone to depression (Levenson et al., 2008). Indeed, the two may be mutually reinforcing, as depression also predicts frequency of reported SCD pain days (Gil et al., 2004).

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http://dx.doi.org/10.1016/j.socscimed.2016.05.029
0277-9536/

It was Brown and Harris (1978) who first drew attention to the potential for a social genesis of depression. In the case of low-income urban women in the UK, they argued for social pathways to depression, with vulnerability factors comprised of stressful life events such as early loss of a mother or unemployment; provoking agents that acted as stressors for more vulnerable isolated women who lacked social support; and protective factors such as the existence of a close confiding relationship. Whilst the salience of this concept for an urban Yoruba-speaking setting and for men as well women requires checking, this in turn leads us to consider possible social pathways to depression, in our case the relationship between sickle cell and depression, albeit in the different socio-cultural context of the Lagos metropolis in Nigeria.

However, applied to SCD, such pathways are not reducible to the idea that culture is a static, monolithic variable that drives the stigmatizing of SCD. SCD in Nigeria has been associated with discrimination ostensibly deriving from supernatural belief systems, such as the *ogbanje* (sick children, reincarnated within families, a process orchestrated by supernatural spirits), and early childhood deaths from SCD show large overlaps with constituencies of children deemed to comprise such malevolent spirits (Nzewi, 2001). However, such cultural ascriptions are historically contingent and context-dependent. For example, Dennis-Antwi et al. (2011) show that, with the implementation of newborn screening for sickle cell over a twenty year period, access to basic medical care, and social support of parent groups, the discrimination against those living with SCD - which is allegedly "cultural" - begins to erode.

In this article we start by using the social model of disablement (Oliver and Barnes, 2012) as a conceptual foil to the dominant position in the existing literature, which tends to locate depression in SCD either in individual clinical symptoms or in (allegedly flawed) individual psychological responses to the condition. We aim to begin not from this perspective, but from an open, critical exploration of experiences of SCD and depression that includes a focus on the social environment. In framing our research strategy from this starting point, we adapt Kleinman's (1988) classic work from social psychiatry to frame a mixed-methods study of questionnaires, individual interviews and focus groups of people living with SCD and depression in Lagos, Nigeria. The focus of both individual and group discussions returned frequently to experiences of stigma, and accordingly the analysis and discussion of the findings also critically draws upon key sociological theories of stigma (Goffman, 1968; Scambler, 2006).

Findings suggest that people living with SCD in Nigeria occupy a socially marginalised and devalued position in which they experience labelling stigma and widespread social disapproval for their perceived inability to live up to a range of social expectations. Aside from direct harmful experiences of social devaluation, rejection and isolation, there is a danger of individuals internalising this stigma and their socially devalued identity with negative impacts on their self-esteem. It is these processes of stigmatization and social devaluation, more than SCD or its symptoms, which emerge in participants' accounts as the primary factors affecting mental health. It was also noted that, in group discussions, participants shared these experiences, formulated challenges to them, challenged negative self-evaluations in peers, and affirmed positives identities associated with having SCD. The implications of these findings for future research and social action are also considered.

2. The social model of disablement and SCD literature

The social model holds that people are dis-abled (verb transitive, opposite of en-abled) not by their "condition" but by social attitudes, physical/social barriers and social conventions, and that it is these that need to change not the person themselves (Swain et al., 2004). To locate the problem in the biology or psyche of the person themselves is, according to this model, to further oppress the person concerned, to "depoliticize the unavoidably political" (Oliver, 1992: 105), and to individualize problems that should properly be seen as social. To this extent, extant literature on sickle cell and depression is rendered problematic.

First, most of the existing medical and psychological literature merely describes an (unsurprising) link between SCD and depression followed by exhortations for clinical interventions to treat depression as well as the SCD itself (Asnani et al., 2010) or to treat depression earlier and more aggressively (Jerrell et al., 2011), sometimes with the hope of improving the disease state as well (Hasan et al., 2003). Secondly, studies frequently locate the "problems" which precipitate depression within the person with SCD themselves, arguing for example that it is complications connected with SCD that place "patients at risk for poor psychosocial adaptation, including depression and anxiety symptoms." (Simon et al., 2009: 317), or that depression is associated with "behavioural inhibition" (Carpentier et al., 2009: 158), or insufficient "locus of control" (Gibson et al., 2013: 451). Thirdly, there is a danger that items on diagnostic scales through which depression is identified might themselves reinforce societal prejudices. For example, the 12-item General Health Questionnaire, used in Ohaeri et al. (1995), contains an item on thinking of oneself as worthless, which as we shall see, is a key social feature of living with SCD in Nigeria, since family, friends, neighbours and strangers are reported to regularly tell people living with SCD precisely this. Fourthly, attempts to link to social variables produce associations but no real insights (see Pawson and Tilley, 1997, on the limitations of variables-based research in establishing plausible and transferable pathways to intervention). Thus whilst, for example, an association between pain episodes and measures of depression may be established, the primary purported solution remains to treat the physical symptoms (Asnani et al., 2010). Indeed, when the expected association of disease severity and depression fails to materialize as expected (such as where those with the allegedly less severe form of SCD, Hemoglobin SC disease, appear to have greater levels of depression than those with the supposedly more severe sickle cell anaemia), then the problem is again located in the psychologies of individuals, with an ascription to the "lower coping mechanisms in those with the less severe form of disease" (Asnani et al., 2010: 6). Fifthly, depression, as with the symptoms of SCD itself (Atkin and Ahmad, 2001), is variable over time. It is not always a feature of SCD, and though some authors raise the possibility of developing resilience (Simon et al., 2009), the focus remains firmly on intrapersonal factors. Finally, limited strategies are then suggested. Few studies refer to broader socio-economic and socio-political contexts (though Hasan et al., 2003 refer briefly to low family income), and, although some studies refer to social support decreasing depressive symptoms (Sehlo and Kamfar, 2015), in others this concept is degraded to mean merely support with appointment-keeping and adherence to health activities (Belgrave and Lewis, 1994).

In summary, much of the existing research into SCD and depression fails to propose appropriate mechanisms to advance the cause of those living with SCD – a situation that, as noted above, has been problematised by many disability researchers and disability rights commentators writing from a social model perspective (e.g. Oliver, 1992). The social model of disability could perhaps more properly be considered the social model of disablement, or to better convey the meaning, *dis-ablement* – the act of placing social barriers in the way of people, not dismantling those that are there, and failing to conceive, enact and enforce processes that better enable disabled people to flourish in their particular societal context. The model is therefore potentially apposite in