Depression: how can NGOs help?

Amelia Mustapha[1,*]

[1] Amelia Mustapha is affiliated with the Expert Platform for Mental Health with a focus on depression and is the immediate past executive director of the European Depression Association

***Corresponding author email: ameliamustapha@hotmail.com**

Abstract

Non-governmental organisations (NGOs) are as varied in activity and structure as the people they represent and support. There are many roles NGOs can play in addressing depression in both clinical and non-clinical settings, at local and international levels. There is need for a more integrated approach to treatment, policy-making and prevention.

Keywords: depression, NGOs, stigma, discrimination, policy, funding, education, prevention, whole-systems, employment

Introduction

Non-governmental organisations (NGOs) are as varied in activity and structure as the people they represent and support. At one end of the spectrum there are very informal groups of people affected by depression who provide peer support, and at the other there are large international umbrella bodies of patient groups, healthcare professionals and policy-makers, which are more formally constituted with a governing board and clear objectives. No matter where these organisations lie on this spectrum they can all play a key role in helping deal with depression.

Tackling stigma and discrimination

This is perhaps the area most associated with NGOs, from awareness-raising campaigns like the annual European Depression Day, to lobbying for legislation that protects against discrimination, NGOs have played, and continue to play, a pivotal role in raising awareness of the realities of depression and challenging society's attitude towards it. Stigma is often cited as one of the most disabling aspects of depression, and this is borne out by the treatment of people, as indicated by the following.

- Despite the prevalence and burden of depression, and the fact that there are effective interventions for it, fewer than half of those affected in the world (in some countries, fewer than 10%) receive such care (1).
- Research (2) suggests that many people, including policy-makers and healthcare providers, hold negative attitudes towards people with depression, resulting in isolation, self-stigma and a lack of services.
- Isolation can be deadly (3), with studies showing that it results in poor mental and physical health as well as early mortality. Self-stigma undermines the ability of people to work towards their own recovery whilst stigma amongst healthcare providers means that opportunities to recognise and treat depression are missed.
- Funding for research and care is out of step with the burden of depression, particularly when compared with other disease areas; again, this is thought to be due to stigma.
- People affected by mental ill-health are over-represented in prisons due to the breakable cycle of poverty, homelessness and prison.

NGOs are also committed to ensuring that adequate education about depression forms a key part of training for health and social care professionals as well as teachers and those working in the criminal justice system, and that there are integrated pathways of care between these disciplines. NGOs can often make the links that other bodies cannot because they take a holistic view of depression prevention and recovery. From Mental Health First Aid International's training programme for the public to the Canadian

Mental Health Association's SPARK training there is a wealth of resources available to the general public and professionals that tackles the root of stigma: ignorance.

Ensuring fair funding and parity of care

Despite the vast burden that mental ill health imposes on people and on economies, many countries continue to neglect mental health care, and the unmet need for treatment remains high. NGOs can call on policy-makers to give depression the importance it demands in terms of resources and policy prioritization. Making mental health a policy priority would enhance people's lives, and have significant social and economic benefits (4). The European Depression Association, Gamian and the Expert Platform on Mental Health (with a focus on depression) are NGOs which have been active in this area, lobbying to ensure that depression and mental disorders are included in relevant legislation e.g. disability discrimination and health and safety at work.

Whilst the large international groups are calling for changes to relevant legislations, national and grassroots NGOs also have a role to play in ensuring that national policies are informed and implemented. Mental health policy, programs and legislation are necessary steps for significant and sustained action (5). If necessary, they should be revised to provide parity between mental ill health and physical ill health, to prioritize depression, to meet the WHO targets for mental healthcare services and ensure budget holders allocate the right level of funding to implement national policy and deliver on the WHO targets (6).

NGOs can also help drive improvements in the quality of life of depressed people by supporting the development of data, knowledge and information. For example, few countries can provide a clear picture of the status of mental health systems. The absence of comprehensive data on quality and outcomes inhibits a full assessment of mental health system performance, resulting in poor policies – in particular, an inability to focus scarce resources on a disease like depression in a way that will lead to improved functioning and better outcomes (2). In the UK, patient group views are included in the assessments of mental health services by the Care Quality Commission, and this helps to give a more reliable and independent view on care and where improvements are needed.

Health technology assessments need to include early dialogue with patients via patient groups to ensure their voice is heard and valued when determining the potential impact of a new treatment. It is particularly important that potential improvements in care are brought to patients in a timely way, and when decisions around reimbursement are made, they take into account the wider social value and real life data. NGOs are a valuable resource in providing access to a large body of patients in an impartial way.

According to the World Health Organization, mental health policy and legislation are the foundation on which to develop action and services but, whilst many countries have mental health policies, they vary widely in quality and content. Furthermore, they are often not implemented (7). NGOs have a huge role to play in holding governments to account and helping to create a 'gold standard' of treatment and care.

Enabling better and earlier access to care and treatment

According to the OECD's recent report on mental health, there is an extremely large treatment gap for depression, with a median 56.3%. As a result, the OECD recommends that governments strengthen and scale-up treatment for depression. The economic case for providing early access to talking treatments for depression has been well established (8) in the UK and proven by the successful Improving Access to Psychological Therapies (IAPT) programme (9). With diminishing resources available, however, it is becoming increasingly difficult to meet these demands and offer the required interventions. With evidence that patient and community groups are effective at reducing depression symptoms through peer support (10), the services and support provided by community and patient groups can be seen as social assets to be used as part of an integrated, cost-effective pathway of care for people with depression. A 'whole systems' approach to primary mental healthcare is currently being piloted in London by the West London Clinical Commissioning Group. This includes peer support, employment and advice services as well as community health interventions being provided by NGOs, and integrated within General Practitioner surgeries and community locations. It gives physicians the tools they need to exploit opportunities for early intervention within health and wider society by offering integrated health, care and employment support to those who are on sick leave or out of work, as well as access to specialized care.

People with depression are twice as likely to be unemployed. They also run a much higher risk of living in poverty and social marginalization (11). In Europe, 1 in 10 workers has taken time off work due to depression, with 36 working days lost per depressive episode. Yet, despite this, one in three managers say they do not have formal support or resources to deal with the problem (12). Depression is a leading cause of lost work productivity, long-term disability and early retirement. 59% of the costs of depression in Europe are indirect. The right work promotes health and enables people to support their families, contribute to society and value themselves. Loss of work can have devastating consequences on the individual and the way they interact with the rest of the world. NGOs can currently be seen to be addressing this, using the highly effective Individual Placement and Support (IPS) model of employment support which includes job retention, job searching and employer support. Other NGO initiatives include giving employers clear guidance and support to promote the wellbeing of their employees and tackle the rise of depression in the workplace by considering depression within a health and safety context. The Target Depression campaign, for instance, brings together large, international employers to share and spread best practice.

For the past 20 years NGOs have been shaping up to face the challenges of depression in innovative ways, co-produced with people affected by the condition. Quality assured, evidence-based and trusted, NGOs should now be taken seriously as partners in the war on depression.

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