

Satisfying Competing Stakeholder Needs in a Depression Awareness Program

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Abstract

The Depression Awareness Research Project (DARP) that was funded to develop, implement and evaluate a community-focussed model to raise awareness of depression has been piloted in 5 locations in Victoria over the last 3 years. The major aim of the project has been to evaluate a community-based model for raising community awareness about depression. The effectiveness of this has been measured using a mixture of qualitative and quantitative methods.

The project is an initiative of the Mental Health Research Institute in Victoria with funding from beyondblue, the national depression initiative.

During the implementation stage of the project community educators were recruited, educated and trained so as to be able to give awareness-raising sessions to their respective communities. To date, over 200 community educators have been trained and they in turn have given presentations to approximately 7000 people.

A number of stakeholder groups have been involved in the project. The community partnerships who provided a base for each of the 5 pilots; the funding body who supported the project; the project coordinators who were responsible for advertising; recruiting and supporting the community educators; the audiences who were the recipients of the depression awareness message, and the community educators themselves.

This paper explores the differing expectations of the various stakeholders within the project and discusses whether their interests have been met by the project. As well, some of the qualitative findings from the project will be presented and their relevance to program effectiveness discussed.

Introduction

The Depression Awareness Research Project (DARP) was conceived by a Victorian former Labor politician who was diagnosed with bi-polar disorder in the early nineties; and subsequently lost the support of his Labor colleagues in parliament.¹ Because of his experience with mental illness he was keen to see if a community based depression awareness initiative would assist in the raising of awareness of depression as well as de-stigmatizing the illness. He is now a consumer consultant at the Mental Health Research Institute in Melbourne, (MHRI) Victoria. His idea for a research project was supported by the Institute and was subsequently funded in 2001. He is the Head of the DARP Project..

Background to the Issue

Increasing public knowledge about depression is regarded as having an important role in decreasing its associated morbidity and mortality.² It is generally agreed that people who are aware and have a basic knowledge about depression are more likely to recognise signs of depression, seek help, and be supportive of the treatment process.³ However recent Australian surveys of mental health literacy indicate a poor awareness of mental disorders such as depression in the general community, particularly with regard to effective treatments⁴ Furthermore, out of the 800,000 Australians who in each year suffer from major depression, 62% of them do not seek medical treatment for their illness.

Data Management

The DARP has been conducted over a three year period in five regions of Victoria. The funding has been supplied by “beyondblue”, the national depression initiative, and the project has been run out of the Mental Health Research Institute in Melbourne. The project is simultaneously developing, implementing and evaluating a community-focussed model of raising awareness and attempting to reduce the stigma of major depression.

The DARP trained and supported local community members in five regions of Victoria (two rural locations and three metropolitan areas). The training package was written by a research psychiatrist and a research psychologist, with input from VICSERV (a Victorian peak body for psychiatric support services), on the communications module and input from consumers and carers.⁵ They simplified the message about major depression under the four headings that *major depression is common; it is an illness not a character flaw; it is serious but ultimately; it is treatable*. These community members or community educators were expected to make presentations to local community groups or workplaces in their particular community about major depression. The community educators were supported by co-ordinators who worked in community-based organisations that were in partnership with the MHRI. There were three recruitment rounds to the project over the three-year period, resulting in 218 community educators across the five regions.

The community educators were expected to talk to up to 100 people each. This could be in the form of a talk to 6 mothers at a mothers group, or to 100 Rotary members, or to groups in the workplace.

Data Collection

Each community educator completed a Depression Literacy Survey (DLS) when first selected into the project, then again at the end of their training and finally after the end of their time on the project. This enabled the researchers to track any changes in their knowledge base over time. At the commencement of each presentation given by community educators, their audiences (secondary contacts) are requested to fill in an abbreviated DLS prior to the presentation. Their telephone number is requested, and if given, MHRI contacted them after three months to ask the same questions, thus seeing if this core knowledge had been retained. The information received from these sources

will enable us to ascertain if this model is a viable method of raising awareness of major depression in the community.

At the end of the project the partner organisations, the MHRI project staff, the project funders and the community educators were interviewed face to face and asked a range of questions on their experiences in the DARP Project.

Data Analysis

The survey data are being analysed using SPSS (Statistical Package for the Social Sciences).

After the qualitative interviews were carried out the notes were transcribed, coded and displayed on Miles and Huberman-style grids⁶. At the same time pertinent comments were highlighted. This is a particularly rigorous way of handling qualitative data.

Focus of this Paper

This paper will concentrate on the qualitative data obtained from the stakeholders involved in the DARP project and will discuss whether the expectations of those stakeholders have been met by the project and in what ways. Conversely it will also discuss the reasons why those needs have not been met.

DARP Stakeholders

There were multiple stakeholders involved in the DARP project:

- The funding body *beyondblue*.
- The sponsoring organisation, the Mental Health Research Institute
- The five community partners who provided a base in the community for the project,
- The project coordinators in the five regions who were responsible for advertising; recruiting and supporting the community educators;
- The Audiences (secondary contacts) who were the recipients of the awareness message, and;
- The Community Educators themselves.

The data from the Community Educators is still being analysed, as is the secondary contact data, so this paper will concentrate on the first four groups of stakeholders.

Partner Organisations

The DARP project was conducted by the MHRI in partnership with four Psychiatric Disability Support Services,(PDSS) two in metropolitan Melbourne; one in a regional city and one in a rural area of Victoria; and one local government in the inner suburbs of Melbourne. It was felt important to have a mix of locations to see if the project was particularly successful in certain environments. There was also a practical aspect to these choices; these were the organisations which were also enthusiastic about the project and wanted to be part of it. All five organisations had representation on the Steering Committee. The DARP Project Coordinators were based in the above organisations, however the employment conditions for the coordinators differed between the organisations. The regional PDSS were the employer body for the coordinators, whereas the MHRI employed the two metropolitan coordinators. The original coordinator for the local government body was employed by the council, however the subsequent coordinator was employed by MHRI and remained external to the council. The coordinator's employment situation did have an effect on the agency's attitude towards the project.

The management of the PDSS's which directly employ the coordinators, commented that there were some problems in terms of the dual accountability situation.

"...this has caused angst because of the competing demands of MHRI and (Agencies name)"

Furthermore those particular agencies expected that the DARP project would have a greater community development role than was the intention of DARP, which was essentially a research project involved in evaluating a community development model and specifically focussed on outcomes in terms of numbers of presentations and secondary contacts spoken to. Whereas the agencies preferred role was to focus on the empowering of local communities. These agencies also suggested that they would have preferred using the coordinator to deliver talks rather than recruiting and training community educators.

"It would have been better to use the project worker for training, rather than relying on volunteers"

On the positive side for agencies the experience with the DARP project has extended their knowledge of the community and given them a resource in terms of volunteer community educators.

...it has opened doors in the community for us. We have enlarged our contacts in the region and have started genuine dialogue"

"We now have an emerging relationship with large employers in the area and we are starting to organise work with them"

There were a number of issues with local government in terms of the DARP which made it an unsatisfactory relationship. The project was not wholly endorsed by all levels of management, and as well, there were a number of management changes during the project:

There was not a defined project structure here at Council with regular meetings etc. and the project has got a bit lost..... it should have had a firmer governance structure."

It was also clear from some of the comments from staff who were trained to become community educators and deliver talks to their colleagues, that some staff were reluctant to come to talks because they felt that management was targeting them personally. So unfortunately, the very stigma the talks were meant to ameliorate was being perpetuated within the organisation.

One of the difficulties with the DARP project was that the research design was developed as the project grew and therefore, quite naturally, there was confusion and misinterpretation as to the direction the project should take. When asked "what were the lowlights of the project" the following was recorded from one agency,

"..Changing the action research model to research outcomes and concentrating more on numbers of secondary contacts."

All agencies felt a concern for the volunteer's health, as a large number of those attracted to the position of community educator were often sufferers of depression.

"Sometimes some of the presenters were ill people, and often took on more than they could achieve."

All of the project partners were united in their feeling that the DARP model has the potential to make a difference. Local Government in particular was supportive of the idea of having in-house educators.

"Using peers is good because of intellectual capital kept in organisation. Outsiders just deliver and go, but insiders talk at morning teas etc."

However a word of caution was given by one of the agencies in terms of over emphasizing the awareness message and blurring the edges between normality and illness.

"I worry that if we get an "over awareness" we might be in danger of pathologising normal sadness and grief. We need to differentiate between this and disabling, ongoing mental illness."

Another agency provided another caution in terms of attributing success to the DARP project.

"We also need to look at whether it was successful because of the way it was delivered. Or was it the media who have been putting messages about depression across the whole community?"

When asked what changes would they have included if they had been able to, agencies pointed to the difficulties they all faced because the project commenced with staff, but no resources and little direction.

"The project started without a road map!"

One of the difficulties faced by the local government was the lack of the project being embedded in the organisation.

"We needed senior management to back the project (change of CEO left project without support" (Do not do (project) during organisation restructure!)

Project Sponsor – MHRI

Several of the staff involved in the DARP were interviewed, the two staff who were involved with the early part of the research project, and the Operations Manager.

The researchers saw it as a good way to bridge the gap between MHRI as a clinical research organisation and the general population. However community research is not without its difficulties:

“Pure research is very neat, whereas community research has so many players involved, so many vested interests so that it muddies the water!”

It was acknowledged by DARP staff that expectations of the agencies and some of the early community educators differed because of lack of clarity from the sponsoring organisation. It was further complicated by the different employment situations for the coordinators.

“Understandings between MHRI and the partners were not clear and the roles of the coordinators had not been made clear to either partners or employees”

Asked whether he would organise things differently if the project was starting now, one of the researchers said,

“I would do it differently now, we did not advertise, just asked around the networks for interested people. Now I would advertise, we might get better people. “

MHRI staff acknowledged that the research project lacked design initially and had not been thought through before commencement.

“We tended to always be catching up. The implementation of the project was not as good as it could have been.”

Project Funder - *beyondblue*

Apart from being the project funder, *Beyondblue* were also involved in developing the instruments for the community surveys which were carried out in each of the five regions before DARP commenced. This provided base-line data for both the DARP project and *Beyondblue*.

It was clear that the funder was, and still is, realistic about what can be expected from the DARP project:

“Not sure that we can expect change in attitudes and behaviours from just a short half hour talk, hopefully there will be an improvement in awareness.”

DARP Project – Regional Coordinators

There was only one region where the DARP Coordinator stayed the full three-year distance. Most of the other regions had two or three coordinators during the project term. For most of the early coordinators it was clear that there was confusion as to the role they were expected to play in the project.

“I was told that the work would be predominantly networking”

“Did not realise that my main role was to be a coordinator of volunteers”

Although in general, the coordinators found their work challenging, most saw it as a project, which has the potential to offer solutions as well as raise awareness. All has acknowledged the “research on the run” aspect.

“Project has been very higgledy-piggledy because we actually began the work before the research and evaluation was set in place.”

For most of the coordinators the important aspect of their work is working with the volunteers.

“Because day to day job is not particularly exciting but working with the volunteers is positive and exciting”

It has also been important not to feel swamped with some of the volunteer’s pain and to remain positive and supportive. For most of the coordinators the project is positive.

“Anything that raises community awareness is good. It is vital to destigmatise the depression issue and we are going a long way towards it”

Some coordinators felt that recruiting and training community educators was not the way to go, one coordinator felt that working within an organisation and training staff was the preferred model. For another coordinator, implementing a pilot in one area and then evaluating before going wider would be preferable. This of course was not the research project on which they were being paid to work on! Most coordinators agreed that their “partner organisation” was supportive, understanding and flexible and in general felt that they had benefited from the DARP Project.

Discussion

It is clear from the above that one of the difficulties of the project initially was the lack of a clear research design. This resulted in some agencies interpreting the project to suit their particular interests in their communities. This meant that some of the partners had a community development focus as their main priority for the project, and were at times hostile to the idea of measuring the outcomes of the project in terms of number of presentations. There were also problems in terms of accountability where some coordinators had primary reporting lines to the partner agency rather than MHRI. It was agreed that the potential of successful outcomes is enormous in the local government area, however it is essential that all levels of management are committed to the project from the outset and that the organisation is clear about the intentions of the project. Assurances must be given to staff that attendance at a presentation on depression does not mean that management have targeted a staff member to be present.

However all stakeholders point to the potential for the DARP model to be successful. For MHRI it has learnt lessons for future projects, where the research design and the intentions of the project will be spelt out before the project starts. The report for *beyondblue* is due by early September. It is hoped that the data analysis will show that awareness of major depression has increased from the pre-presentation survey to the post presentation survey for the secondary contacts. If this is the case, whether this result can be totally attributed to their attendance at presentations designed to raise their awareness of depression will be another issue. A strong advertising campaign from *beyondblue* has resulted in an abundance of information on depression across our media. To isolate the gains in knowledge on depression to the presentations only

is a difficult task. On the positive side, wherever the information is coming from, the important thing is that awareness levels are being raised about this major illness.

¹ Prof. Copolov D., Cole N., Chamley W., Trauer T.,(March 2001) The Development of a Training Approach to Enhance the levels of Awareness and Understanding of Depression in the Community. A Proposal from the Mental Health Research Institute to beyondblue

² Commonwealth Department of Health and Aged Care (2000). National Action Plan for Depression, Mental Health and Special Programs Branch, Canberra.

³ Sundrum S, Bellingham K, (2002) Promoting Positive Mental Health: A Practical Guide to Planning, Implementing and Evaluating Mental Health Promotion Programmes. Mental Health Research Institute, WHO Book Chapter.

⁴ Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P (1997). "Mental Health Literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Medical Journal of Australia, 166:182-186.

⁵ McGuinness.,RutterA.,SundramS.,BellinghamK.,Morton-Allan E., Chamley W.,Trauer T. and Cole N., "The Depression Awareness Research Project" (Paper given at the THEMHS Conference, August 2003.

⁶ Miles, M. & Huberman, A. (1994) "Qualitative Data Analysis. Thousand Oaks, Ca: Sage