

Australian mental health consumers' priorities for research: Qualitative findings from the SCOPE for Research project

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Abstract

Background There is growing acceptance of the importance of the consumer viewpoint in mental health research. Previous studies have identified differences in research priorities between researchers and mental health consumers in Australia defined broadly. However, little is known about the research priorities of consumers with specific mental health conditions.

Objective The aim of this study was to explore Australian mental health consumers' priorities for depression and bipolar disorder research.

Design Focus groups with consumers and individual telephone interviews with consumer advocates. Participants were asked to discuss the topics they believed were priorities for depression or bipolar disorder research. Transcripts were thematically analysed using NVivo 7.

Setting and Participants Ten people with depression and 19 with bipolar disorder participated in face-to-face focus groups held in three Australian capital cities. Five participants with each disorder participated in online focus groups. Five Australian consumer advocates with experience of depression and six with experience of bipolar disorder were individually interviewed by telephone.

Results Participants raised a broad variety of topics for research. The most salient themes included the need for research on medication, and lifestyle and psychosocial influences on depression and bipolar disorder.

Conclusions Participants' priorities reflect an interest in a holistic approach to mental health research that examines the influences of everyday life and psychosocial influences both on the development and on the management of these disorders. Their focus was on research that explores individualized care and the active role that consumers can play in their own care and recovery.

Introduction

The need for the research community to prioritize research topics is increasing as competition for limited research funding grows. A number of research priority-setting methods such as expert opinion, disease burden, health costs or analyses based on existing research have been described in the literature, but many have failed to include the consumer perspective.¹⁻⁴ It is difficult to justify a research priority-setting process that is not informed by the views of the people whose lives are affected by the illnesses being studied. It has been argued that to be relevant and effective, health research design and implementation must be informed by end users, who are the best placed to identify existing gaps and how their needs may best be met.⁵⁻⁸

In a study carried out in 2002 for the Australian Commonwealth Department of Health and Ageing, Jorm and colleagues examined research priorities for mental disorders in Australia.^{9,10} The research included a comparison of existing published research with the priorities of a range of stakeholders including consumers. However, participants rated survey items derived from the existing research base, limiting the scope for the development of new ideas for research priorities. In addition, participants provided priorities for mental health research in general rather than for specific mental disorders.

The Study of Consumer Priorities (SCOPE) for Research project was developed to inform future directions for research on depression and bipolar disorder in Australia from a consumer perspective. This study reports findings from phase 1 of the project, a qualitative exploration of the topics that consumers identified as priorities for research.

Methods

Consumers' ideas for research were explored through face-to-face and online focus group discussions with people with personal experience of depression or bipolar disorder, as well as individual telephone interviews with Australian mental health advocates. All participants self-

identified as experiencing depression or bipolar disorder, and all the groups and interviews were conducted by the first author who disclosed to participants her own status as a mental health consumer. Ethics approval was provided by The Australian National University (ANU) Human Research Ethics Committee.

Participants

A total of 50 consumers participated in the study. Complete demographics were only collected for face-to-face participants ($n = 29$). Strict privacy guidelines discourage members of the bulletin board on which the online groups were conducted from revealing any personal information. However, some information regarding gender and age was available to administrators ($n = 10$). Advocates were not asked to provide demographic details, so only gender information was available for this group ($n = 11$). Approximately 70% of participants were women and most were aged between 40 and 60 years, although both younger and older adults were represented. Limited educational data available suggested the majority of participants were educated at a tertiary level.

Face-to-face focus groups

Initial recruitment was via an invitation sent through the ANU Depression & Anxiety Consumer Research Unit (CRU) register mailing list, a national register of people who have expressed interest in participating in CRU research projects. Additional participants were recruited by advertising in the local newspapers, through mental health networks, support groups and key non-government organizations.

A total of 29 people participated in six face-to-face focus groups held in three major Australian capital cities. Focus groups were held separately for people with experience of depression ($n = 10$) and those with experience of bipolar disorder ($n = 19$).

Online focus groups

Focus groups were also conducted with registered members of CRU's online depression and anxiety mutual support community, *BlueBoard*.

BlueBoard is an anonymous online bulletin board for people personally experiencing or caring for someone experiencing depression or anxiety and related disorders.

A message was posted in the 'Notices' forum inviting Australian members to participate in the priorities project. Members of the CRU register with a current email address were also invited via email to participate in the online groups. A total of 10 consumers participated in the online focus groups: five with depression and five with bipolar disorder.

Mental health advocate interviews

Individual telephone interviews were conducted with 11 mental health consumer advocates from around Australia. Advocates were recruited through email advertisements to key mental health organizations such as the peak Australian national mental health body, the Mental Health Council of Australia. All participating advocates had personal experience of depression (five participants) or bipolar disorder (six participants) and self-identified as fulfilling a formal or informal mental health advocacy role.

Procedure

Face-to-face focus groups

Focus groups were conducted in accordance with a semi-structured protocol, which ensured consistency across groups whilst still allowing the natural flow of discussion and ideas. Topics raised by participants were summarized on a computer connected to a digital projector. Participants were invited to comment on or correct items as they were listed to ensure accurate reflection of the ideas raised, as these items formed the initial coding framework. All sessions were also audio-taped and transcribed for analysis.

At the commencement of each group, participants were provided with a definition of research to ensure clear understanding of the intent of the current project. They were then asked to discuss the question 'What aspects of (or topics about) depression/bipolar disorder do you think we should research?' The question was framed only for the disorder with which partic-

ipants had personal experience (depression or bipolar disorder). Participants were encouraged to brainstorm any points they thought relevant and discuss them with the group. When the brainstorming was exhausted, participants were given a prompt list of topics developed by researchers, based on that used in the previous priorities project,^{9,10} and invited to discuss and comment on the items. This order, allowing consumers to suggest their own topics before commenting on those developed by researchers, was designed to identify novel topics that may have been missed if conversations were directed by the pre-prepared list from the outset. At the conclusion of the discussion, participants were asked to write down which of the topics discussed would be their top three priorities for research.

Online groups

The procedure for the online groups followed the protocol for the face-to-face groups with some modifications for the text-based environment. As the group was conducted on an asynchronous bulletin board rather than in real-time 'chat', discussions extended over 4 weeks and participants could visit at their leisure, reflect on ideas and revisit topics over a much longer period than ordinary real-time focus groups allow.

Mental health advocate interviews

Mental health advocates were posted a project kit that included the prompt list in a sealed envelope with instructions it was to be opened when requested during the interview. Interviews were conducted using a speakerphone and audio-taped in the same manner as the focus groups and followed the same semi-structured procedure. Ideas raised were summarized on computer and read back to interviewees for clarification and to ensure accuracy.

Analysis

Qualitative analysis was conducted by the first author using NVivo 7. Using a thematic analysis approach, the materials were coded using both *a priori* and *in vivo* codes.¹¹ In excess of 380 codes

were generated across both disorders in the initial stage of analysis. This involved both the collation of the summary items developed by participants during data collection and inductive coding from the transcripts. During the second stage of analysis, the codes and associated discussion were examined to combine similar concepts both across and within disorders. However, codes unique to each disorder were also preserved. Care was taken to ensure the label for the combined code still reflected the language used by participants. In the final stage of the qualitative analysis, the 141 individual topic codes were organized into broad themes. Some themes related to items on the prompt lists; other areas were novel to consumers' ideas. Additionally, during the final stage of analysis, participants' written 'top three' responses were collated into the broad topic areas to prioritize the research topics identified.

Results

Results presented are the 16 broad thematic areas, ordered by relative importance to all participants as indicated by the 'top three' responses. Table 1 summarizes the 16 major themes and presents the number of participants who included topics in each theme on their priority lists. Differences in

emphasis and ideas and the amount of discussion generated for each disorder are also described where appropriate. Quotes from participants are accompanied by a unique identifier comprising a combination of letters that designate their mental disorder (D = depression, BP = bipolar disorder), their role (A = advocate, C = consumer), the forum or interview type (FG = face-to-face, OF = online forum, I = interview) and a number within the resulting category.

Medication

Medication was the thematic area that appeared in the greatest number of 'top three' lists across the groups and interviews. Much of the discussion about medications surrounded the issues of undesired effects, that is, immediate side-effects and long-term effects such as organ damage.

I think a lot of consumers talk about things like easily explainable side effects and the doctor says 'oh yeah well, that's life',... I know people that get really really bad side effects from medication and I suppose it's no surprise that they sometimes want to go off them. [BPAI4]

Participants expressed the view that there is insufficient evidence on what works, resulting in doctors taking a haphazard approach to prescription.

Topic area	Total participants	People with depression	People with bipolar disorder
Medication	14	7	7
Lifestyle and psychosocial influences	12	3	9
Causes and risk factors	12	7	5
Education and awareness	10	8	2
Treatment	9	7	2
Health professional issues	9	5	4
Services	8	3	5
Diagnosis	8	4	4
Employment	6	1	5
Management	5	—	5
Research issues	5	2	3
Description and characteristics	4	2	2
Effects of mental health problem	4	—	4
Government policy and funding	3	1	2
Alternative therapies	2	—	2
Psychological therapies	1	—	1

Table 1 Number of participants including topics in top three priorities

One thing I find with medication is it's not as well planned. You know, it's sort of very hit and miss, very experimental, what works, how long it's going to work, how much ... [DCFG10]

Lifestyle and psychosocial influences on depression and bipolar disorder

Another of the highest priority areas, particularly for participants in the face-to-face groups for bipolar disorder, was lifestyle and psychosocial influences on mental health. Participants were interested in research into a wide variety of specific topics including social factors such as relationships and community involvement; physical influences such as exercise and physical ill health; and factors such as stress and its management.

Isolation, introspection, dead end jobs and dysfunctional family and personal relationships appear to have detrimental effects on an individual's ability to function within society. [BPCOF3]

Participants indicated that many facets of everyday life could play a strong role in both mental health and mental illness. They believed research should explore how these factors influenced and connected with their mental health.

Lifestyle, people being too busy and too stressed, too many things happening too often, no time for relaxation, working too hard, travelling too far and in stressful traffic conditions ... how many of these situations could be a trigger for depression? [DCOF5]

The benefits of communication and support groups were often suggested as an extension of the importance of social relationships in discussions of lifestyle and psychosocial influences.

Causes and risk factors

Research into causes and risk factors for depression and bipolar disorder featured strongly in the priority lists for both disorders but generated much less discussion than the themes already described. Suggestions tended to be phrased as an unelaborated statement of fact rather than an idea generating further comment or debate. Most of the discussion that occurred

on this theme was related to genetic versus environmental factors in mental illness and how they may interact.

Research into interaction between nature and nurture. Between genetics on one side and the environment and as we all know it's also the interaction. But especially today it seems to me everything has been taken up by genetics and I wish that we could go back, take a bit of distance here and set the problem in a ... setting. [DCFG7]

There was also a widespread perception that knowing the causes and triggers of depression and bipolar disorder might lead to more effective treatments.

Education and awareness

Issues in the area of education and awareness about mental illness were a high priority for participants with depression, particularly those in the face-to-face groups and advocate interviews. The overall message was that participants perceived a very high need for research into effective education campaigns to improve the understanding of mental illness. There were two main subthemes: (i) knowledge about depression and bipolar disorder and (ii) attitudes towards these conditions. Participants expressed concern that there is a lack of knowledge in the general population and amongst health professionals about depression and bipolar disorder.

I still get so angry at the lack of understanding amongst the medical profession and society as a whole. Despite so many well-known people coming out and saying they suffer from depression and the ads for beyondblue ... people still don't get it. [DCOF5]

These concerns were strongly tied to a consensus that stigmatizing attitudes towards people with mental illness remain a large problem.

... there's two kinds of responses ... One is 'You're crazy and we don't want anything to do with you ...' And the second kind of response is 'Oh, boo hoo, you have depression, look we've all got problems, go away. Grow up, just you know pull yourself together.' [DAI11]

Treatment

Treatment was discussed both as a general topic area and with respect to more specific components. As described above for causes and risk factors, there was less discussion around treatment compared with other areas. Many participants with depression felt it was an obvious high priority for research, and it was included in priority lists for face-to-face groups, the online group and by one advocate. It was also discussed in many of the focus groups and interviews on bipolar disorder, but only two advocates with bipolar disorder included treatment in their top three priorities.

A common theme in many focus groups and interviews was whether treatment would be more effective if tailored to causes and symptoms. Participants were interested in research that explored individualized treatment to replace what they perceived as the current 'hit-and-miss' approaches to clinical treatment.

If clinical depression is a combination of genetics, biological factors and circumstance, then it may be that the success or otherwise of various treatments is related to the cause. Is there a link between cause and cure? [DCOF1]

Health professional issues

Much of the discussion about health professional issues was not focused on research priorities directly, but the suggestions that emerged have implications for the development of research projects in this area. The most common specific topic from this area that was included in participants' priority lists was the education of health professionals, especially by consumers. As described in the section on medication, participants believed professionals such as general practitioners (GPs) often took a haphazard or hurried approach to treating depression and bipolar disorder and that they could benefit from the insights provided by listening to consumers both as patients and as educators.

I think a lot of them need, of the GPs, need more education on how to deal with depression, but they also need to have more professional time to give a patient. [DCFG1]

Consistent with the treatment theme, participants believed research into individual treatment plans developed in partnership with GPs might provide insight into more effective treatment. The overarching concept running through the topics about health professionals was that there were certain issues such as professional education that needed to be addressed at the level of the individual professionals in addition to the wider service level as discussed below.

Services

Compared to the thematic areas already presented, the theme of services was not as broadly discussed and did not feature as strongly in the priority lists. This was another theme where participants' suggestions were not always specifically focused on research topics but nevertheless have important implications for the development of research projects.

Similar to the health professional issues theme, participants felt that research was needed on the education required to improve services and the role of consumers in that education, service development and improvement.

It's well and good to develop a service, but if you're not in contact with people who that service is for ... how can you really develop something that's really going to be appropriate for those people? [DA15]

The other specific topic for services research that was common in participants' top three priorities concerned the access to and quality of services. In particular, many advocates discussed concerns about the problems they had observed whilst working in public mental health services, but it was consumers from the face-to-face groups who considered this topic a high priority.

Diagnosis

As for the services theme, the scope of discussion about diagnosis as a topic for research was more limited than other themes already described. Participants with both illnesses expressed concern that people often experience lengthy delays in diagnosis, and misdiagnosis.

I think some studies said there was something like a 15 year delay between onset and diagnosis of bipolar. I'd like to see some research that could either cut that down, to allow say for instance, GPs to do earlier diagnosis... [BPCFG19]

However, there was also some disagreement regarding the usefulness of diagnosis. One advocate with bipolar disorder felt that sometimes health professionals were 'overzealous' in diagnosing mental illness.

What do diagnoses do? They tend to be very sort of painful for the patient and ... I'm sometimes wondering if doctors are a bit overzealous in diagnosing. [BPAI4]

Thus, whilst people felt that diagnosis could be a path to effective treatment and recovery, they emphasized the importance of speed that was tempered by care and accuracy.

Employment

Employment was a theme that received greater attention from participants with bipolar disorder than from participants with depression. The primary focus of this discussion was related to the need to research the interrelationships between employment and mental health and illness. Participants were interested in both how mental illness can affect employment and how employment can affect mental health.

In my experience ... individuals who participate in society have a better chance of attaining mood stability and achieving a level of functionality. The flip side for bipolar people is the tendency to sine curve, biting off more than one can chew while hypomanic and setting unsustainable levels of performance and expectations for employers. [BPCOF3]

Management

One of the novel themes (not included in the researcher-prepared list) to emerge was the management of mental illness. The primary theme of discussion was the strategies that people employ to self-manage their disorder and allow them to lead a 'normal' life, paired with a questioning of what it means to recover.

It's interesting because there's people who [manage their condition for] amazingly long times and seem to do perfectly well, so what's the ... ticket, what's the clue to that? [BPCFG13]

Even though it did not feature as highly in the priority lists, issues on management did generate substantial discussion in a number of groups and interviews, particularly for bipolar disorder, and was clearly a significant topic.

Research issues

The majority of discussion on the research issues theme centred on the importance of consumers as researchers, and this was reflected in the priority lists. Four of the five people who included this topic area in their priorities specifically listed consumers as researchers.

Much of the discussion concerned whether consumer participation in the research process made a difference to the way in which results were analysed. Participants acknowledged that the current project was conducted by a consumer researcher and suggested this could result in a better understanding and connection with the issues.

... it would be interesting to do it, essentially what you're doing now. Include people who are bipolar in the analysis process. Because they ... would intuitively have some understanding of what's going on...headwise. Would be able to put that perspective more easily into the analysis. Whereas someone, doctor going on the outside may not be able to provide such a rounded perspective. [BPCFG18]

Description and characteristics

Description and characteristics were widely discussed across a number of groups and interviews, but topics in this area were included in fewer priority lists. Two main subthemes emerged from the discussions on description and characteristics: the symptoms of the disorders and their course over time. In particular, participants were interested in the constellations of non-specific complaints that may be used to form depression and bipolar disorder diagnoses and how they may change over time.

Mental health is, you know a continuum and a lot of the time symptoms and things are fluid aren't they? [BPCFG8]

Participants with bipolar disorder also linked this topic area to diagnosis. They noted that often diagnoses changed over time because of overlapping characteristics of bipolar disorder with others such as attention deficit hyperactivity disorder (ADHD) and schizophrenia.

Effects of mental health problem

The effects of having a mental health problem included impact both on the self and on others, particularly carers. This topic area was identified exclusively by participants with bipolar disorder and the four participants who included this theme in their lists of top priorities all nominated research into the effects on carers and how to help them as important.

... all the families (as far as I'm aware) we're pretty much in the dark as to what exactly to do. There may be a few ideas but there's not a lot of formal procedures that they can be given that then help them work out what to do... It affects everybody around us, it's not just us. [BPCFG17]

Government policy and funding

Research into government policy and funding was another novel theme raised in several groups and interviews. Many participants expressed suspicion that government initiatives were not based on sound research findings and were not subject to proper evaluation.

Why governments don't use research findings: We already have lots of knowledge (early ID, support and treatment plans, professionals working together, medications, talking therapies, models for management, cost to government in fixing later greater than getting in at ground level etc) so why isn't sufficient funding applied? [DCOF3]

One of the solutions several participants proposed to this problem was researching how consumers could be included in the political processes that determined how services are developed and funded.

Alternative therapies

The subject of alternative therapies was raised in a number of groups and interviews for both depression and bipolar disorder but did not generate a great deal of discussion. Participants mentioned a wide range of alternative therapies such as music, art therapy, massage and acupuncture as topics for research. However, typically, participants discussed interest in research on the use of alternative therapies as an adjunct to conventional treatment.

... consumers, whilst accessing evidence-based things like medication and CBT and that sort of thing, they probably also use a range of other different therapies or ways of managing their depression...I don't think something necessarily has to be evidence-based for it to be an important sort of treatment. [DAI5]

Psychological therapies

Psychological therapies were rarely raised as areas needing research, and only one participant, an advocate with bipolar disorder who had a special interest in bibliotherapy, included this topic area in the list of priorities. Counselling, cognitive behaviour therapy and mindfulness also received brief mentions in one of the focus groups for depression and two of the advocate interviews for bipolar disorder, raised during discussions about treatments and strategies to remain well.

Other important topics

There were numerous specific topics that did not fit any particular broad theme, some of which featured in the top priorities lists. These included 'brain research', help-seeking, prevention and positive aspects of depression and bipolar disorder.

Discussion

Four thematic areas received support as research priorities by around a quarter of participants. Medication, lifestyle and psychosocial influences,

causes, and education and awareness were all endorsed in the greatest number of top three priority lists across the face-to-face and online groups and the advocate interviews and were the focus of significant discussion. Three of these areas – medication, causes, and education and awareness – included discussion in response to items on the researcher-developed prompt list. However, lifestyle and psychosocial influences consisted exclusively of consumer-developed ideas for research and represented a novel topic area. In particular, participants focused strongly on the need for research on the role of social relationships, peer support and life stresses in mental illness.

Social and welfare issues have also emerged as important in UK studies of consumer research priorities, particularly those conducted by mental health consumers, suggesting these topics may be of importance to mental health consumers on a broader scale.^{12,13} However, the themes raised in these UK studies were wider social issues such as the influence of housing, employment and finances on mental health, rather than the social relationships that were the focus of the current study.

The topics raised by consumers in this study frequently overlapped with existing research topics on the prompt lists, but their unique perspective also resulted in both novel ideas and '...subtle differences in orientation'.¹⁴ A good example of this difference in orientation is consumers' views on medications. The stakeholder survey for the earlier Australian priorities study included a general item on medications for mental illness, and the item subsequently included in the researcher-developed prompt lists for the current project suggested 'side-effects of medications' as a potential research subject.^{9,10} Whilst participants did discuss this topic area both in general terms and in response to the prompt item, they also discussed concerns about the safety of taking medications long term and the need for a tailored and personalized approach to the prescription of medications. Although the latter is more closely linked to services than research, participants believed closer ties between research and services are

necessary to effect the greatest change. In their Delphi study of the priorities of various mental health stakeholder groups, Owens *et al.*¹⁴ reached the same conclusion.

Rose and colleagues also found that participants in their mental health consumer focus groups discussed medications critically and expressed an interest in research into how people's lives are affected by medication and how medication use may be minimized.¹² The authors contrasted their findings with those from a previous UK mental health priority-setting study that was conducted by clinical academics in which medications were not mentioned. They speculated that consumers may not have been comfortable discussing issues about medications in the presence of psychiatrists in the earlier study, whereas the Rose *et al.* study was conducted by consumer researchers. The current study was also designed and conducted by consumer researchers. As Rose¹⁵ described it, the 'double identity' of consumer and researcher can be difficult to manage, but both the researchers and the participants in the SCOPE for Research project felt that this made the researchers more 'connected' with the discussions and more likely to understand the issues because of a shared perspective. As suggested by Rose *et al.*,¹² this perception of the researchers as part of the group rather than a professional outsider may have encouraged participants to be more forthcoming and discuss issues in greater depth.

It is significant that many of the topic areas considered important by participants in the current research such as medications and treatment were not prioritized by any stakeholder group, including consumer representatives, in the earlier Australian priorities study.^{9,10} In addition, new topic areas such as lifestyle and psychosocial influences on mental health and management emerged from the current study. Such findings emphasize the value of a qualitative research approach to understanding consumer priorities for mental health research and informing the development of items for use in quantitative surveys of consumer priorities. Important consumer perspectives may be missed

if research in this area relies only on lists generated by academic researchers.

The SCOPE for Research study included interviews with mental health advocates as well as face-to-face focus groups and online focus groups for data source triangulation.¹⁶ It was felt that as a result of their representative roles, mental health advocates may have a broader perspective on mental health issues. The online groups allowed participation from consumers outside the three major capital cities in which the face-to-face groups were conducted. The three sources were intended to be complementary rather than comparative, and overall there was remarkable agreement on the top priorities. Few areas were the focus for any particular type of participant, with the exception that most responses that included the effects of mental illness and employment were from participants in two of the face-to-face groups for bipolar disorder. These participants were primarily members of active support groups that regularly dealt with issues such as problems for carers and employment difficulties, which may explain this emphasis. The majority of advocates also included education and awareness in their top three, a finding that is not surprising given that raising awareness and educating the public and health professionals are all part of mental health advocacy roles.

Limitations

There are several limitations to this phase of the SCOPE for Research project. Although the research used a combination of sampling methods and included participants from different regions of Australia, the majority of participants were well-educated women of middle age. Thus, it is possible that the themes and the priorities elicited in the current study were not representative of the broader consumer population.

Another potential limitation is the subjectivity inherent in qualitative methods. The current research attempted to address the issue of the accuracy of analysis by using summaries developed by consensus during groups and interviews as the basis for coding, having a consumer researcher act as facilitator and conduct the

analysis and by asking participants to write down their top priorities for use in identification of the most important themes.

Finally, as already mentioned, participants sometimes found it difficult to separate priorities for research from gaps in services. Similar to the findings of Owens *et al.*,¹⁴ participants drew on their own experiences in services when suggesting research topics in this area, and some of their suggestions may reflect a failure to implement research findings rather than a gap in the research *per se*.

Conclusion

Participants were strongly engaged with the SCOPE for Research project, participating in lengthy focus group and interview discussions. The topics that consumers raised frequently were variations or new perspectives on traditional research and clinical areas, informed by their personal experiences and interests. Some research may already exist in the general areas prioritized by consumers in this study, but there remains a perceived need amongst consumers for further work on a holistic approach to mental health research that examines the influences of everyday life both on the development and on the management of these disorders and that explores a focus on care of the individual.

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Conflicts of interest

None

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