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Capturing the experience: Lessons of consumers and carers in rural mental health education

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Research

Capturing the experience: Lessons of consumers and carers in rural mental health education

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Abstract

In 2012, the School of Nursing, Midwifery and Indigenous Health at Charles Sturt University in New South Wales, introduced guest lectures from consumers of mental health services and their carers. These lectures were placed within the introductory mental health subjects of both the Mental Health Nursing and Paramedic undergraduate programs. This paper describes this experience by combining the recollections of six key stakeholders: the non-government organisation (NGO) carer support organisation CentaCare Wilcannia-Forbes, a consumer, two carers, a student and the academic involved in the program. Each provided responses to five aspects: the background to the project, the gains from the experience, the personal hopes and concerns when the project was proposed, the perceived value of the project and finally thoughts about the future of the project.

Risks are recognised at an individual level for students, carers and consumers of a re-traumatising nature, and of inadvertent reinforcement of pre-existing stereotyping or stigmatising positions. However, overall, the project was well regarded and is considered worthy of continuing, supported by some research to identify the germane elements.

Keywords

consumer and carer teaching; nursing and paramedic learning; lived experience of mental illness; NGO support service; experience of collaboration; rural and remote mental health

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Introduction

'I have a brother who has suffered a lifelong and chronic mental illness. When my brother is in a quiet place, and has his coffee and tobacco, he sometimes becomes quite calm. In a situation like this, my brother has a very profound wisdom.

Many years ago, I had to go into Sydney to collect my brother off a train, and take him to the Eddy Ave bus terminal, to make sure he caught the right bus home. We found a quiet place with a seat amongst the sandstone in Eddy Ave. We had a lot of time to while away, a coffee shop close by, and we settled down to some conversation about our childhood, and the difficulties as young adults trying to find our way in a world that was alien to us, with the burden of believing we were worthless and not very smart.

At the time, my brother was very active with Alcoholics Anonymous (AA) and I was running a state-wide support organisation. Both of us were doing this voluntarily. We arrived at a point where we were discussing the benefits of being able to pass on our experience and the responsibility we have as individuals, to pass on our accumulated knowledge. In reference to what my brother and I had learned, to make our lives more liveable and comfortable, and getting some satisfaction from what we have learned my brother said... "and once you have got it, the only way to keep it, is to give it away".

A statement like this may be interpreted in many ways, by many individuals, but my interpretation is this: To spend upwards of two decades and more searching for answers, self-analysing, seeking medical assistance, asking questions, observing the way people think and behave, learning to fit into society by trial and error, in my brother's situation, fighting a dreadful illness and undignified addiction, as well as learning to allow ourselves to be imperfect and human, as well as many other factors, leaves one with a great deal of satisfaction.

I strongly believe those of us who have managed to fight our way out of the darkness of the mire, and have achieved a reasonable quality of life on the other side, have a responsibility to our fellows in general, to pass on to those less fortunate, at the right time and in the right circumstances, the knowledge we have accumulated, in an effort to make an individual's life better than it may be at that time.

The knowledge I have accumulated is mine, it belongs to me, I worked hard to get it and my brother worked harder than I with a much greater handicap. It gives me a great deal of satisfaction to know I have learned what I have learned. It gives me no satisfaction to stay quiet when I meet someone, or I am engaged in conversation with someone, friend or stranger, who may have need for the knowledge I have accumulated. Therefore, the only way I can keep this knowledge, is to give it

away, as often as I can.' (John, a carer for a person who has a mental illness)

Background of collaboration

The School of Nursing, Midwifery and Indigenous Health at Charles Sturt University undertook a major revision of two undergraduate mental health subjects in late 2011 for implementation in 2012. The subjects were part of two separate undergraduate bachelor programs – the Bachelor of Nursing and the Bachelor of Clinical Practice (Paramedic). Both subjects were at that time coordinated by the same academic, Denise McGarry.

These programs were revised to incorporate recovery principles. Recovery principles have a significantly different meaning in mental health than remission from (psychotic) symptoms. Recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery - hope, healing, empowerment and connection - and external conditions that facilitate recovery - implementation of human rights, a positive culture of healing, and recovery-oriented services (1).

The aim of incorporating these principles was to enable students to develop a person-centred and strengths-based approach to their future practice with people who experienced mental health issues and with their carers. Orientating students to recovery principles as a means of conceptualising mental health care was based on reinforcing the central tenets of hope, the importance of an individually defined meaningful and satisfying, self-management, and acceptance that recovery may be attained in the on-going presence of recurring or residual problems. One pedagogical strategy was to expose students to the lived experience via a range of media including written accounts, documentaries, film and guest lectures (2-5). The lived experience is recognised as an authentic manner to support recovery principles and when engaged in a narrative teaching process has shown some efficacy in supporting student learning (5). This paper is an initial report of the experience of these guest lectures.

There is an increasing body of refereed literature that demonstrates the benefits of including input from those with the lived experience of mental illness in preparation of health professionals (6-8). These benefits are recognised as improved understanding of the experience of mental illness for individuals and carers; reduction of stigmatising beliefs; improved understanding of the nature of mental illness itself; increased appreciation of the experience of admission to, and treatment within, mental health services; and how these services could be improved from consumer involvement in the education of health professionals (9).

With these objectives in mind, an approach was made to the Family and Carer Mental Health Program – a government funded partnership between CentaCare Wilcannia-Forbes and Western New South Wales (NSW) Local Health District. CentaCare Wilcannia-Forbes was the local non-government provider of mental health carer support programs. This resulted initially in the involvement of a single carer for 1 year. In the second year this expanded to include a consumer and her carer.

Kathryn, Family Carer Mental Health Support Worker and Education Officer recalls: “The Family and Carer Mental Health program was approached by Denise – Lecturer in Mental Health at the School of Nursing Midwifery and Indigenous Health from Charles Sturt University in late 2011. The discussion was an introduction to the concept of carers and those living with mental illness, being involved in teaching the nursing and paramedic students by relating their lived experiences and their journey. Providing a humanised aspect to the student’s education, carers would have a valued role in assisting students to see to hear about the experience of living with mental illness.”

The contribution to the student programs was uniform – a single session for each cohort placed within the second lecture of the session. The time allocated was 30-60 minutes at the end of a 2-hour lecture. Placement in this part of the program enabled students to be prepared for the unique nature of these guest lectures and to be introduced to recovery model principles, which were the rationale for the inclusion of the guest lectures. By scheduling at the end of the 2-hour session, questions and answers and informal discussion could be more readily accommodated even if exceeding the allocated lecture time. The introductory material presented to students was known to carers and consumers prior to their guest presentation.

The content of the guest lectures was guided by the individual’s level of comfort with describing their lived experience of mental health issues. The subject of each talk was determined individually depending on the issues the carers and consumers deemed important for beginning health workers. Risks were identified, including self-disclosure that could be uncomfortable or unnecessary for student learning and possible inadvertent reinforcement of pre-existing stigma where students had not yet had an opportunity to identify or challenge stigmatising beliefs. A risk was also possible that the material may be upsetting for students particularly for those who also had lived experiences of mental health issues. Students were informed of these possible risks and support mechanisms for them identified.

As Kathryn (family worker) recalls: “It was agreed that the carers would attend as guest lecturers and were allocated a time to attend and address students. Carers were asked about how they would like to be presented to the group ensuring that

carers were supported in their experience. Support provided was acknowledging a need for anonymity; first names were used in introducing participants. Family and Carer Mental Health Program staff attended all collaborative sessions to ensure that carers had access to emotional support if needed.”

A further component of this project was the preparation of a reflective descriptive paper, to inform interested parties of the experience in a regional university of integrating consumer and carer input with two undergraduate health professional programs. It was hoped to add to the published literature in the field, particularly that addressing the experience within paramedic preparation. The authors were the original three carers and consumers, the family care support worker, the academic and at the suggestion of John (carer), a paramedic student was involved to ensure the voice of a student. The student was recruited by purposive selection without being representative of the opinion of all students. He was known to the academic as an engaged student who had participated in all aspects of the subject and to have a profile as a student representative within the course.

All authors independently responded to an agreed set of mutually generated topics. These topics form the headings of this article. This approach was designed to maintain the independence and authenticity of responses while addressing consistent topics. The written responses were prepared approximately 6 months after the lectures had been delivered and in anticipation of further guest lectures in the coming teaching session. This also ensured that the student author was not confounded by subject assessment considerations. The paper was reviewed as a team, taking care to clarify but not alter the responses. The academic assumed responsibility to responding to journal requests for review.

Collaboration in further research is ongoing to provide more rigorous understanding from both the student body and those engaged in lecture provision.

Gains from experience

The response from all student cohorts was overwhelmingly positive. Respectful attention was evident in all sessions. Questions were thoughtful and considerate. Informal conversation following the session was extensive. These sessions were singled out in the end-of-session subject evaluations as a high point. Changes in student attitudes, especially any amelioration of stigmatising were not measured.

Neil, a second year student assessed the effect of the session in this way: “The primary gain from this sort of exposure is the first person, lived experience of the consumers and carers. This is something that no textbook, or PowerPoint presentation can provide. They are the first-hand accounts from people for whom

the experience is not simply theoretical. Instead it is a daily, weekly, monthly fact-of-life. Something that has to be confronted all of the time. I believe that the realisation of this fact was one of the stronger messages that resulted from listening to the presenters.”

Chris, consumer of mental health services says: “I was able to put forward my point of view as to how I had been treated unfavourably on some occasions by medical people and how this affected me. I was able to give the students a better understanding of my needs when I am sick. I have a lot to offer medical professionals if I am given the opportunity to speak. I have been sick for a long time and I felt a release on both occasions [guest presentations] because I was able to do something constructive with what I have learned.”

Kathryn (family worker) observed: “Carers have been able to stand up and fight the sense of stigma around mental illness, build resilience (which is one of the principles of recovery), build on their self-confidence and self-esteem. Empowering them in a process where they feel heard and valued. Carers were able to relate their individual experiences without direction from the university or CentaCare Wilcannia-Forbes. Their contributions were as little or as much of what they wished to share without outside editing or an overpowering agenda.”

From a Charles Sturt University perspective, the relationship with carers, consumers and CentaCare Wilcannia-Forbes are highly valued. Current literature has identified the value for student learning of education informed by consumer and carer input (9). This project represents a part of this.

Neil (student) again: “The message was delivered to an audience largely made up of first time university students, the vast majority being in their early 20s age group. This means that for most, this was their first opportunity to meet, listen to and interact with those who cope with mental illness, and just as importantly those who have to care for them - long before the ambulance arrives, and long after the ambulance has left. It's almost strange to think, that after 2 years of study, this is the first time that the student body has been able to interact with ‘real people’ who had ‘real problems’ instead of high-tech mannequins that are used as patients. This coupled with the realisation that despite extensive training received, not all people's health problems can or will be solved in the back of an ambulance.”

There are significant challenges for student equity in this project. Although the sessions were recorded and so available to all campuses and to students studying by distance mode, the experiences are significantly different. Asynchronous delivery removes the possibility for interaction, reducing students' ability to seek clarification for issues.

Gains were recognised by all parties in the project that centred on authenticity. For the student, input was not homogenised as

demonstrated by his comment that this was an encounter with ‘real’ people and problems. Chris (consumer) appreciated that the understanding gained from her experiences was afforded genuine expression in a manner that might see others benefit. Both the family worker and academic viewed the lectures as authentic expressions of recovery principles.

Personal hopes and concerns when asked to participate

A common response by the consumer, the carers and the student, was some trepidation when invited to participate. For Chris (consumer) this was a concern at the task of communicating her perspective clearly, tempered with excitement at the opportunity to do so. The trepidation for John (carer) centred on the academic environment, but for Mary (carer) it was the potential loss of privacy and concern for any effect this may have for her daughter. Confrontation with the reality of the experiences of mental illness – including a concern centred on violence - was identified by Neil (student).

Neil (student) expressed this in the following way: “The students could be forgiven for having concerns about personal safety prior to the start of the discussion - being largely unfamiliar with the implications, the fear of the unknown, fear of the unexpected.”

Kathryn (family worker) responded to the suggested collaboration in the following manner: “As advocates for carers of those living with mental illness, the Family and Carer Mental Health Program wished to support carers to have the opportunity to create change in the thinking of health professionals and health care providers in regards to how carers are treated and involved in the care and treatment of their loved ones. Anecdotally, carers frequently recount that they still feel they are left out of treatment decision making, care planning and ongoing medical care of their loved ones. Carer involvement in sharing their experiences with students provided an understanding that those living with mental illness need to have functioning support networks such as family, clinical support and other supports within the community to aid in their care and recovery.”

Chris (consumer) says: “When asked to participate I felt quite honoured and somewhat in awe of the task ahead. It was my hope that the knowledge and experience I have accumulated over the years would be of benefit to both students and people like myself who suffer mental illness. I was also looking forward to passing on my point of view, and needs as a consumer, to the students.”

John (carer) reports: “I have been given two opportunities in 3 months to attend Charles Sturt University at Bathurst, to talk to several ambulance trainees and several trainee nurses. The subject was ‘Caring for the mentally ill at home’.

This was a double honour, in as much as I was invited to speak at a university and to be able to impart knowledge to people entering a highly skilled profession. It was also particularly satisfying to be asked to do this as a layman, with a layman's experience. It was also very satisfying to know the students listened intently and asked a lot of questions after my talk. It is even more satisfying to know the students will take the knowledge I have given them into their professional lives.

I truly believe the university has done a wonderful thing by calling on laypeople in the community to pass on their experiences to aspiring professionals. This action can only do good to help professional medical people better understand the afflicted individuals and the care they need. If it is not already being done, I would like to see this opportunity extended to other people; with different illnesses, for example, people who suffer ongoing skin disease can also suffer mental illness by way of depression. I wish to extend my full appreciation to the people who gave me this opportunity to, as I said before, 'give it away'."

Mary, a carer for a person who is a consumer of mental health services, emphasises different aspects of this invitation. "When asked to consider submitting my experience as a carer for a professional journal, I experienced a range of mixed feelings. Uppermost, any desire to illuminate for others the reality of the journey accompanying someone with a mental illness is tempered with the knowledge that no single experience mirrors another's. Moreover, while I have been travelling the road as a carer for over 20 years, there always remains my desire for anonymity. I have an instinct to shield not only myself but, more importantly, the one I care for – my 38-year-old daughter. In addition, my experience, for now, is taking place in a calmer period, without the harrowing extremes of midnight police visits, drug overdose, attempted suicide, rebuffs from a dysfunctional health system, verbal and/or physical attack that can, so often, be encountered by fellow carers in both of my monthly, carers' sharing sessions. Therefore, my hopes and expectations are to provide both some level of awareness of the complexity of mental illness and perhaps, some measure of support for those involved in any way, in the vortex that is mental illness."

The value we see from the project?

Chris (consumer) reports the value of the project for her "lies in the certain knowledge that my experiences, including those of medications that did or did not work and being misdiagnosed for many years, will feed down to people with the same and similar illness that I have."

Neil (student) presents an adamant point-of-view: "Is there any way to say that the opportunity to gain that first hand life-lived experience would NOT be of value to the student body? The answer is, of course, a resounding no! The benefit

is incalculable - to listen to representatives of a group of people that in a few months, will become our patients. In this interactive setting students can insert him or herself into the situation, assess their own responses in light of the training provided in lectures and study to this point."

The sentiments expressed underscore that the experience of providing and having guest lectures from consumers of mental health services and carers, were seen as valuable. This confirmation is regarded as indicative of the findings reported in the published literature (8-11) and supports continuation of this project. However, it must sit within a supportive framework that expands and contextualises them.

Future directions

Chris (consumer) reports: "It is my hope that more lay people will be asked to talk to students about the way they have had to live with their illnesses. I hope to see the experience give a better quality of life to others. I hope I have passed on a better understanding and tolerance for mentally ill people. I hope the experience may be passed on in print to expand the opportunity for others, consumers and scholars, to benefit. I hope that others may feel the deep sense of satisfaction I have from passing on their stories in this way."

"What has been gained from the experience so far is both encouraging and depressing," Mary (carer) comments. "I am encouraged to see those who are prepared to listen and share their own experiences. It is only by bringing these stories in to the open that we can help our society to see that those with mental illness are human. They are people, not the monsters or the failures as so often portrayed or blamed by the media. On the down side, I am depressed by the enormity of the problem – there are so many to be helped; there are too few professionals to cater for the needy; there are too few funds to adequately cover need; too many mistakes are made. Therefore, my hope for the students is that they can make use of the opportunity presented by these life-experience talks. I see the talks as a valuable learning tool providing students with an opportunity for interaction, questions and answers that may not otherwise occur in a text research situation."

What I have gained from the experience is a little harder to quantify. It is not simply a cathartic exercise as there, beneath the surface, is a compulsion to talk: to warn, explain or ask for understanding becomes part of many carers' life. Students I've spoken to seem appreciative of the experience. Therefore, if these talks help in some small way to develop a necessary empathy for those needing help, an insight into what may be achieved and an awareness of how the way ahead is difficult for those trying to cope with a constantly morphing health system, then this is, for me, the measure of the program's value and success."

Kathryn (family worker) suggests, "By including a carer's experience in student education before students begin their careers in the mental health profession, it is hoped that they develop compassion and empathy for not only those living with mental illness but also their carers. The Family and Carer Mental Health Program would like to see collaboration with Charles Sturt University continue, with the possibility for further research into the value of carer/consumer contributions to teaching nursing and paramedic students."

A final word from Neil (student): "It almost goes without saying that there are only two things that need to be expressed in regard to future directions. The first is that the continuing availability of such interaction is a must. Secondly, that the pool of available participants is fostered and encouraged to grow. The greater the range of experiences that the student group can listen to, relate to, and therefore integrate into learning with real-world application, the more valuable the opportunity will become."

This preliminary reflective review from participants in guest lectures demonstrates support from all stakeholders. It is acknowledged that these individuals' enthusiasm needs to be further investigated to ensure that it translates to learning outcomes. It does confirm findings from published literature that supports this approach in mental health preparation for health professionals. Further, it shows that those asked to share their lived experience may also find the experience positive.

Limitations of this study

Limitations for the article include the non-representative status of the student author and the delay from delivery of guest presentations until authoring of the reflections. The delay may have altered the nature of the recollection, or may be more considered than an immediate response and might be a worthy topic of further investigation.

Competing interests

The authors declare they have no competing interests. Each author of this paper have completed the ICMJE conflict of interest statement.

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