



## Exploring hope: Its meaning for adults living with depression and for social work practice

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### Abstract

Mental health consumers are increasingly challenging deficit focussed constructions of mental illness, which conceptualise depression as a psychopathology with associated connotations of abnormality and disease. The emergence of the recovery paradigm facilitates the possibility, indeed the hope, of recovery from serious mental illness. Social work has much to offer this shifting mental health context, drawing as it does on holistic understandings of individuals and on perspectives such as strengths, resilience and empowerment. This changing practice environment supports the need to examine individual consumer experiences of depression and recovery in order to better inform the helping relationship. This paper informs this area of practice by exploring meanings and constructions of hope from the perspective of mental health consumers with depression. The research suggests that by incorporating hopefulness into interactions between mental health consumers and clinicians, there is the potential to enhance both the wellbeing of the consumer and the quality of the consumer/clinician relationship.

### Keywords

*hope, depression, recovery, consumers, social work practice, service delivery*

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### Introduction

Traditionally, discourse about mental illness has been framed within a medical model, which conceptualises depression as a psychopathology with associated connotations of abnormality, deficit and disease, and a preoccupation with medication. Within this medical framework, consumers are *patients* who require *medication* and *treatment* to *manage* their illness. Potentially, their individual identity can become consumed by their diagnosis, which then becomes a self-fulfilling prophecy – once diagnosed as mentally ill, a person can only ever be mentally ill.

Professional literature, first-person consumer narratives and the consumer participants in this study support the notion that this traditional

medical model is ‘detrimental to consumers’ self-efficacy and sense of hope’ (Carpenter, 2002, p. 86) and that it visualises ‘the client as a diagnosis rather than an individual’ (Deegan as cited in Carpenter, 2002, p. 87). Rapp (1998) asserts that treatment of mental illness has too often been focussed on symptoms and deficits, and fails to recognise and engage the whole person. Effectively, the dominant medical model promulgates the silence and invisibility of the experience of depression itself.

However, the contemporary mental health practice context has changed significantly since the emergence of the recovery vision in the early 1990s (Anthony, 1993) and the increasing prominence of consumer voices. The recovery vision, described as ‘a deeply personal, unique

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process of changing one's attitude, values, feelings, goals, skills and/or roles' (Anthony, 1993, p. 15), holds as a central tenet the philosophy that, 'people with psychiatric disabilities can and do recover' (Carpenter, 2002, p. 88). Clearly *recovery* has multiple individual meanings, but includes the hope that the individual can build a life worth living (Anthony, 1993; Deegan, 1988). The notion of recovery has been received with much enthusiasm by both consumers and clinicians in the mental health field, because it 'embodies a hopeful view of the future and suggests modes of intervention that reflect humanistic values and principles of social justice' (Sullivan & Rapp, 2002, p. 247).

Allott and Loganathan (2002) suggest that consumer movements and first-person narratives (see Deveson, 1998; Jamison, 1996; Wurtzel, 1994) are responsible for first raising awareness of the possibility of recovery from serious mental illness, as well as courageously personalising the experience. In the current practice context, consumers are taking an increasingly active role in determining the management of their illness; a role endorsed by mental health policy and guidelines.

Within this context, an exploration of the meaning of hope for adults with depression seems both timely and necessary. This paper draws on a research project which aimed to develop understandings of how hope is conceptualised in the mental health context, as well as raise awareness of the value and importance of hope in interactions between people with depression and mental health clinicians. The research hypothesised that by fostering and incorporating realistic hopefulness, based on the consumer's vision of hope, into interactions between the mental health consumer and clinician, there was the potential to enhance both the quality of the consumer/clinician relationship and the wellbeing of the consumer.

### **Constructions of hope and depression in the literature**

A review of the professional literature illustrates the many attempts that have been made to produce a universal definition of hope – a task that has not been successful. The literature represents hope as an intangible, complex, multidimensional and interpersonal concept,

variously described as a feeling, an emotion, and a belief. Sources of hope, such as religion and spirituality, are examined. Characteristics of hope are described, and the therapeutic strategies required to foster and encourage hope are outlined. There is even reflection upon the impact that the therapist's/practitioner's hope has on consumers' treatment (Adams & Partee, 1998; Anthony, 1993, 2000; Darlington & Bland, 1999, 2002; Deegan, 1988; Kirkpatrick, Landeen, Woodside & Byrne, 2001; Morse & Doberneck, 1995; Russinova, 1999). Hope is variously conceptualised as a subjective experience, a unique experience, a capacity, a need, a state, a change-agent, a source of reformation, a resource for life, and a perceived sense of possibility (Farran & Popovich, 1990; Herth, 1991; Hinds, 1984; Holdcraft & Williamson, 1991; Miller & Powers, 1988; Owen, 1989; all as cited in Kylma & Vehvilainen-Julkunen, 1997).

Although Bloch and Singh (1997) suggest that 'hope has always been a vital factor in psychological life, even in the face of the harshest circumstances' (p. 279), until relatively recently hope has been largely absent from constructions of mental illness. However, the emergence of the recovery vision in the 1990s has raised the profile of hope in relation to mental illness. The recovery vision underpins McCann's (2002) definition of hope in the context of mental illness, where hope is 'a multidimensional personal construct with cognitive and affective dimensions that reflect a realistic appraisal of the situation and anticipation of a good outlook' (p. 84). Central to this definition is the assumption that hope gives comfort, helps in the endurance of illness and enhances the transition to wellness.

Depression is 'a syndrome – a collection of symptoms and signs that commonly occur together' (Bloch & Singh, 2001, p.163), and is characterised by both emotional and physical features. William Styron (1991) offers a vivid insight into the experience of depression in his own first-person account:

*Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self – to the mediating intellect – as to be very close to being beyond description. It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode (p. 7).*

Psychiatric classification systems such as DSM-IV-TR (American Psychiatric Association, 2000) and ICD-10 (World Health Organization, 1992) offer a range of signs and symptoms which assist in diagnosing depression. Interestingly, *hopelessness* is not named, suggesting the inherent challenge that exists in scientifically classifying and assessing this condition.

Narrow, stigmatising and pathologising constructions of depression, which incorporate a preoccupation with deficit, effectively exclude hopefulness in that they do not allow for 'the intangible, immeasurable spectrum of personal beliefs and moral or immoral convictions' that shape individual constructions (Goldstein, 2002, p. 28).

## Method

The research which this paper stems from is based on a constructivist epistemology and an interactionist theoretical perspective, both of which conceptualise meaning as being individually constructed via interactions with others and society. Such an epistemological approach assumes that people with depression respond to society's stigmatisation of mental illness, which leads to the construction of individual identities which are inferior to those who are not mentally ill and which are characterised by an absence of hope.

Four individual semi-structured interviews were undertaken with adults who have a diagnosis of depression. All were female, aged between 40 and 55 years, and time from diagnosis was from 3 to 25 years. They were accessed via purposeful sampling of mental health support networks, and all described themselves as 'well' at the time of the interviews. A series of thematic prompts was used during the interviews in order to 'facilitate talk' (Darlington & Scott, 2002, p.56), including: 'Tell me a bit about yourself... and your experiences of depression'; 'What does hope mean to you? How does it feel? What gives you hope? Where does it come from?' and 'How is your hope explored when interacting with mental health professionals and do these interactions encourage your feelings/experiences of hope? How?' The resulting narratives were interpreted using thematic analysis, a process which involves identifying themes or concepts.

## Findings: Stories of hope in the context of depression

Permeating the participants' narratives were themes of disconnection (the mask of depression), isolation and despair (loss of hope), meaning-making (conceptualisations of hope), *being* versus *doing* (the helping relationship), and reconnection (finding hope). These themes, articulated in the words of the consumer participants (utilising aliases), are used here to present the research findings, but should not suggest that all the voices told a consistent story. In accordance with a constructivist epistemology, it was possible to identify consistencies, exceptions, contradictions and paradox throughout the data.

### *Disconnection: The mask of depression*

Infusing constructions of the experience of depression was the concept of disconnection: from reality, normality and hope. Consumers portrayed this disconnection as the mask of depression; the facade they create to hide and silence their depression despite the energy and effort it takes to do this. This meant being 'a really good pretender and a really good actress' (Debbie), or pretending to be physically sick rather than admit to being depressed, which would have been perceived as a 'weakness, so you didn't talk about it. [I've spent] forty years of lying about it and pretending to be a so-called normal person' (Gael).

The mask of depression was embodied by feelings of self-doubt, low self-esteem, lack of self-belief, and worthlessness; feelings which were accompanied by self-blame and punishment whereby consumers were unable to accept that they were 'okay,' or 'able,' or 'smart,' despite being told this by others. Depression also represented a disconnection from things that would normally be hope-giving. For Nicole, who described hope as 'a lightness of my body,' depression meant that 'it could be a beautiful sunny day but I can't enjoy it, but on a better day I can see the sun and feel a bit happier about it.'

### *Isolation and despair: Losing hope*

Losing hope was strongly related to the experience of depression and, whilst all consumers had experienced suicidal ideation, for

Debbie and Gael loss of hope manifested itself in suicide attempts.

Nicole described the experience of losing hope when she was severely depressed: 'There just isn't any hope. You think that you're going to be like that for ever and that's not... it's not worth living.' Her loss of hope was also associated with a sense of isolation from everyday things and a loss of joy: 'When I'm really depressed then – normally I look forward to seeing him [her boyfriend] – but I don't look forward to seeing him, which makes relationships really hard.'

Compounding Edna's loss of hope was a lack of understanding from others: 'They'd say, "it's time to get up out of the bed now and move" ... and you know ... sometimes you just can't', whilst for Debbie it was related to the challenge of not conforming to the 'stigma bracket of stupid and pathetic and all those things that go along with the feelings of when you're depressed ... not worthwhile, nobody really cares what I think....'

### ***Meaning-making: Conceptualisations of hope***

As reflected in the literature, hope was a difficult notion for participants to articulate and conceptualise. Commonly, both hope and depression were metaphorically and dichotomously depicted. Visual metaphors of hope included: 'ray of light,' 'sunshine,' 'clouds parting,' 'shaft of light through the clouds,' and 'light at the end of the tunnel,' Nouns such as 'energy,' 'strength,' 'essence,' 'potential,' 'goals,' 'optimism' and 'joy' were expressed, as well as verbs such as 'desires' and 'wants.' These conceptualisations were juxtaposed alongside metaphors for depression such as, 'deep dark hole,' 'bleak,' 'dark place,' 'darkness,' 'abyss,' and 'the worst place in the whole world.' The place that depression takes Gael to 'is quite foreign' and represents 'a flatline kind of living,' whilst for Debbie, depression 'is a terrible roller-coaster, getting back up, coming back down.'

The vocabulary of hope included *coping*, with an inability to cope described by Edna as, 'I'm ... not coping ... I want to die.' Being able to cope was perceived as hopeful and an inability to cope was perceived as being related to the experience of depression: 'I feel bad, I feel as though I'm

not a good person because I can't do the things like I usually do them' (Nicole).

Similarly, *future* was contained in consumers' language of hope. Both Nicole and Edna presented anticipatory or future focussed ideas.

*When I was growing up I used to think, oh well, when I leave school it'll be easier or I'll be happier. When I went to work I'd think, oh, it'll be better when I have a boyfriend, and the next stage would have been, oh, it'll be better when I'm married, and the next would have been, it'll be better when I'm at home with a child ... that was sort of my hope.* (Nicole)

Being given a diagnosis or label of depression helped to make meaning and give hope for all consumers. It gave them permission to feel the way they were feeling and offered an explanation for those feelings. Diagnosis enabled Gael 'to come out of the closet' and finally take off the mask of depression; she could stop acting. For others, the diagnosis offered relief and understanding: 'Oh, I can actually stop pretending, I can actually get some help, I can actually live ... and I hate labels but it was a necessary label for me' (Edna).

Paradoxically, when some consumers felt that the diagnosis was becoming a self-fulfilling prophecy, in that depression was seen to constitute their whole identity, it caused them to lose hope. The meaning-making which comes from the label of depression, therefore, is coupled with the need to accept the depression, whilst not allowing it to become the dominant identity:

*[I had] to learn to accept it is a part of who I am ... and that was really hard because for a while it was who I was. I was depression. I was ... the person with depression. Now I am the person who does this, who does that, and I also have depression. It is part of me and sometimes I hate its guts ... it belongs to who I am ... and I live with that.* (Edna)

### ***Being versus doing: Hope and the helping relationship***

All consumers suggested that hope is not a subject that is explicitly spoken about in the helping relationship; the focus is more on improvements in functioning and a discussion of how things are going at the time of the interaction.

Unsurprisingly perhaps, it is clear that the helping relationship can be hope-destroying, or

at least not hope-giving and sustaining, particularly when framed solely within the traditional medical model. All consumers described interactions with physicians and psychiatrists where their preoccupation with medication was detrimental in that it prevented simply allowing people to talk about their experiences. For Debbie, this was depersonalising: ‘The first thing they do is get the prescription pad. They were treating the symptoms of my illness – they weren’t treating Debbie.’

The value of medication for treatment of depression was acknowledged by all participants; however, consumers described their ongoing struggle with the need to both take medication and stay on medication in order to manage the depression. Nicole has tried many different medications in the hope of finding ‘a cure.’ Accompanying the medical model’s preoccupation with medication was what consumers described as a focus on the here and now. For Edna this was ‘all about treating me, who I was then ... not about who I could be in the future.’ Similarly, the context of the helping relationship – both timing and setting – appears to impact quite significantly upon the presence of hope within the relationship. For example, in an acute setting such as a hospital psychiatric ward, the challenge is to bring hope into the interaction in the context of the acuity of the depressed experience.

What gave hope to consumers in the helping relationship was named inextricably and fundamentally as the nature of the relationship itself, whereas it was perceived that clinicians valued their ability to offer therapies and strategies as the primary method of making hope visible for consumers – an incongruence represented here as the dichotomy between *being* and *doing*. For Nicole, all that mattered was that the ‘professionals’ were able ‘just to help me.’

Although the value of therapy was acknowledged, what gave hope in the helping relationship from the consumers’ perspective related to feeling validated and understood. Nicole described this as a need for kindness, not being pushed, and ‘knowing that there are lots of things we can’t do and being gentle with us.’ A perceived lack of understanding from professionals led Debbie to conceptualise

electroconvulsive therapy (‘this radical treatment’) which she was extremely fearful of, as ‘a last resort and a tiny bit of hope.’ What she really wanted was ‘somebody to say to me, you will get through this, but there was nobody ... nobody understood.’

All consumers spoke of the hope that comes from developing networks and gaining support, whether from a partner, children, friends or a professional. Gael described reaching out to professionals and needing both a supportive and a reciprocal relationship which contains a degree of mutuality:

*I’m pouring out my life to that person and they’re kind of sitting there and just being ‘the professional’ ... it’s not going to work for me ... I want somebody to share a little bit of themselves ... some sort of human to human talking ... I hope to have some feeling of equality.* (Gael)

### **Reconnection: Finding hope**

The knowledge that people can recover from depression is strongly connected to finding hope and is seen, by Gael, as ‘an antidote to hopelessness.’ Consumers associated recovery with gaining insight about the depression and finding strategies to monitor and manage it. For Nicole this means being ‘kind to myself’ and ‘taking things a bit more easy’ on days that are not so good, and giving herself permission to seek help within a given time frame, rather than just ‘struggling on’ which is what she would have done previously. Insight also means accepting the limitations associated with depression, such as the number of hours that some consumers can work.

For Gael, Debbie and Edna, reconnection to hope comes from their role as mental health community educators, which enables them to be heard and make mental illness visible, thereby reducing the stigma of mental illness for younger generations. All three women acknowledged that mental illness is hidden in both their own and their parents’ generation. This invisibility and denial has sparked a passion for educating others about mental illness, which in turn offers them hope:

*You can stand there and you’re living proof that mental illness is episodic and it doesn’t mean you’re going to be locked away in an institution, it doesn’t mean that you can’t go on to achieve or follow your*

*dreams ... you're living proof that it's okay ... we don't attach that stigma to ourselves.* (Debbie)

The opportunity to influence the helping relationship was the reason Debbie agreed to participate in the research:

*If this can help you [the author] become ... a professional who will bring that hope ... and discuss it with people, rather than just take a clinical point of view ... that would be fantastic ... because people [with depression] are reaching out for ... hope.* (Debbie)

Nicole lives her hope through her children because 'they're well, so hopefully they will remain well' – an acknowledgement of her fear of them inheriting a genetic predisposition to depression. Hope also comes from the normality of having a relationship and supportive friends with whom you do not have to pretend, or mask, the reality of depression. Consumers' hope is connected to looking to the future and achieving 'normality,' such as having a partner who understands depression (Nicole) and clawing back a little bit of the role of mother and wife (Edna).

### **Implications for social work practice**

Given the increasing prominence of consumer voices in both the practice and policy arenas of mental health, it is vital that these voices have the opportunity to influence social work practice; something this paper and the underpinning research has sought to enable. In both the literature reviewed (Deegan, 1988; Deveson, 1998; Jamison, 1996; Styron, 1991) and in the research itself, consumer voices clearly articulated the need for a helping relationship which is based on human to human connection, and which overtly incorporates hope, from the perspective of the individual.

The possibility of recovery offers hope to consumers and clinicians alike. Within the context of the recovery paradigm (Adams & Partee, 1998; Anthony 1993; Deegan, 1988), it is crucial that clinicians seek to understand both the meaning of hope from the perspective of the consumer, and also how that hope is maintained for people experiencing severe mental illness.

It is essential for clinicians to reflect upon their own constructions of hope since these have the capacity to influence meanings of hope within the helping relationship. Use of the strengths

perspective and the conceptualisation of mental illness within a recovery paradigm also offer opportunities for fostering an environment of realistic hopefulness, based on the consumer's vision of hope. Indeed the strengths perspective suggests that both consumers and clinicians will always find hope, even in the face of the despair of depression, since the search for strengths reconnects to past coping, resilience, dreams, successes and hopefulness.

Perhaps the key tasks for social workers in the mental health field are the acknowledgement of the centrality of hope in the context of depression and the acceptance that hope is a complex, multidimensional and individually constructed phenomenon. As Margolin (as cited in Rossiter, 2000, p. 33) argues, 'when social work establishes one reality, it necessarily blocks others.'

Consumer voices in this study, as well as the literature (Darlington & Bland, 1999; Deegan, 2000; Ellis & King, 2003; Styron, 1991), suggest that the nature of the helping relationship is central in influencing mental health consumers' constructions of both depression and hope. Consumers are reaching out to be heard and understood, whilst professionals are responding by offering therapeutic strategies, techniques and prescriptions. This preoccupation with *doing* (diagnosing, medicating, and offering therapy) does not support consumers' need for clinicians to simply *be* (to listen, validate, support and seek to understand meaning). It is clear that this juxtaposition between *being* and *doing* represents an inherent tension in the helping relationship. Exploring this tension in more depth offers promise for closer and more hopeful interactions.

Social workers must endeavour not to close off *any* dimension which is hope-giving to consumers, and this can only be achieved via a dialogical relationship which enables the consumer to explore and articulate their individual conceptions of hope. There is no singular or universal approach to incorporating hope into the therapeutic relationship; however, an acceptance that it is a vital concept for mental health consumers, and a commitment to exploring its meaning, will benefit both clinician and consumer.

## Further research

This paper draws on Honours research, which is inevitably limited in both its scope and depth. While the insights gained herein are valuable, further research that explores hope in the context of therapeutic dyads between matched pairs of consumers and clinicians may be valuable in terms of deepening the knowledge gained. Such research may provide more insight into the nature of the helping relationship and specifically illustrate elements of interactions which are either hope-giving or hope-destroying. Also a constructivist approach to understanding suggests the need to explore the impact and influence of structural components such as gender, culture, age, and socio-economic status upon conceptualisations of hope for mental health consumers and mental health clinicians.

## Conclusion

The themes that permeated the data gathered from the research participants, as well as the literature about hope and depression, illustrate the complexity of the concept of hope, the stigmatising experience of depression, the significance of the recovery paradigm, and the nature of the helping relationship with its inherent capacity to either stifle hope or, by drawing on strengths and resilience, to facilitate experiences of hope.

It is clear from the consumer narratives that the journey of depression begins with invisibility, silence and hopelessness, and spirals backwards and forwards towards visibility and hope. The invisibility and silence is promulgated by societal expectations of people with depression – expectations which then compound the hopelessness and support constructions of despair, weakness, and shame. The stigmatising experience of depression effectively excludes hope from the lives of those with depression. Similarly, the traditional medical model of mental illness, which has constructed depression as a psychopathology, is not conducive to fostering constructions of hope in consumers. This narrow stigmatising construction of depression, with its preoccupation with *doing*, effectively excludes hopefulness.

The challenge to all mental health clinicians is to proactively incorporate hope into their interactions with consumers, and perhaps when

hope seems unattainable to those consumers, to hold on to hope on their behalf – to be ‘hope carriers’ (Darlington & Bland, 1999, p. 22).

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