Advancing self-determination with young adults who have schizophrenia

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The research examined how community mental health nurses promote self-determination with clients who are experiencing an early episode of schizophrenia. The study used grounded theory methodology incorporating interviews and observations. The study took place in the community, in rural and regional New South Wales, Australia, and involved clients and community mental health nurses. The findings show that the promotion of self-determination is dependent on nurses educating clients about their illness and well-being, and fostering self-control. The development of a reciprocal relationship, or alliance, between nurses and clients is implicit in advancing self-determination. The implications of the promotion of client self-determination for education, clinical practice and research and these are discussed.

Keywords: education, participation, psychotic illness, schizophrenia, self-determination, wellness

Accepted for publication: 11 March 2003

Introduction

The notion of self-determination is derived from the moral principle of autonomy, which comes from the 17th century adoption of the Greek autos (self) and nomos (law). Self-determination is the way in which individuals make decisions about their lives (Pearsall 1998). Within the context of health care, self-determination has been defined as clients’ involvement in decisions that impinge on their lives in the absence of constraints imposed by others (Valimaki 1998), reducing dependence on health care professionals (Dickerson 1998), and the right to make autonomous decisions concerning their own well-being (Yeo & Dalzier 1991). Deci & Ryan (1985), proponents of the theory of self-determination, claimed that self-determination is integral to the establishment and exercise of intrinsic and extrinsic motivation. In their view, the concept extends beyond self-control. It is an innate need of all individuals to be self-determining, and to have the capacity to choose whether to take a particular course of action. This is an empowering process, premised on the ability to control one’s destiny, to influence and respond.

Client self-control, through self-determination, can only take place within a mutual or equitable relationship between nurses and clients, where the relationship is based on an alliance between agents rather than an asymmetric expert/lay relationship. An alliance implies shared understanding in decisions about care (Barker 1999), an approach supported by Barnes et al. (1995) and Holloway (1998). There are conflicting reports, however, about the value of this type of approach. In some studies, it has had favourable consequences for clients
of client self-determination is difficult to achieve, because a
and others (Johnstone 1994, Barker 1999). The promotion
behaviours not undermining the well-being of themselves
others in quite self-determined ways. Clients' rights to self-
participate in wellness-related behaviour may be viewed as
in accordance with the wishes of health professionals
(1998). However, mandating for client self-
determination does not guarantee its practice. Szasz
claims that there is ample evidence to show that psychiatric practices fail to comply with the require-
ments of the Act.
The preoccupation of nurses with self-determination is
most appropriately understood within the historical con-
text of their professional dominance over clients, and the
need to reconceptualize the relationship between pro-
fessionals and clients, who must now be perceived as
active partners, rather than passive recipients of care
(Playle & Keeley 1998). The promotion of client self-
determination requires recognition that an unequal
relationship exists between clients and nurses, and this
distinction is maintained by the rhetoric of collaboration
and self-determination (Kuipers 1996, Pavis et al. 1998).
As a consequence, clients describe services as coercive
and providing limited choice (Lindow 1993, Lucksted
& Coursey 1995). Because of their precarious situation,
clients may have limited opportunities to exercise self-
determination. The case management system, for
instance, is a health care worker initiative that evolved to
manage growth in demand for community mental health
services, not because of a central intent to improve cli-
ents’ quality of life. It is primarily a system for manag-
ing care that is contrary to the principle of clients’
involvement in their care (Rhode 1997).

There are limits to client self-determination. In enhanc-
ing this approach, nurses assume that clients both want,
and are free to choose, wellness-focused behaviour in
accordance with the wishes of health professionals
(McEwan & Bhopal 1991). The decision by clients not to
participate in wellness-related behaviour may be viewed as
counter to the intent of nurses wishing to promote well-
ness. For instance, they can choose to remain dependent on
others in quite self-determined ways. Clients’ rights to self-
determination are also conditional on their decisions and
behaviours not undermining the well-being of themselves
and others (Johnstone 1994, Barker 1999). The promotion
of client self-determination is difficult to achieve, because a
balance must be established between promotion of the con-
cept and intervention (McMurray 1993). This balance can
be particularly difficult to maintain with clients who have
mental illness because of the unpredictable nature of their
illness. Self-determination requires that clients are able to
behave and think in a rational manner (Buchanan & Brock
1989), but this can be compromised by severe mental ill-
ness such as schizophrenia. Irrespective of the nature or
severity of illness, clients are entitled to self-determination
(Valimaki & Leino-Kilpi 1998, Nordgren & Fridlund
2001), as it is an important aspect of their quality of life
(MacGilp 1991).
The centrality of self-determination to the process of
nursing is demonstrated by empirical evidence which
shows that the perception of personal control plays a cru-
cial long-term role in influencing health and well-being
(Rodin & Langer 1977, Schultz & Hanusa 1978, Rodin
1986). As far as can be established, there have been no
previous studies that have examined how community
mental health nurses promote client self-determination
within the context of recovery from schizophrenia. Given
that the literature shows client self-determination has an
important role in helping clients recover from illness, there
is a need for research which examines the strategies that
nurses use to foster this approach with clients who have
schizophrenia.

Aim
The purpose of this study was to report the processes that
community mental health nurses use to promote client self-
determination within the context of recovery from an acute
episode of psychotic illness. The findings are taken from a
larger study about the unique ways these nurses help young
adults who are experiencing an early acute episode of
schizophrenia, to recover from the episode and lead fulfill-
ing lives.

Research design and methodology
The study used grounded theory methodology because of
the need to obtain a clear understanding of the acquired
meanings, interactive structures and social processes that
underpin the way nurses promote self-determination in
this context. Grounded theory enables theory to be gener-
ated from the data, and allows existing theories to be
modified or further developed (Charmaz 1990). Its episte-
mological assumptions are derived from symbolic interac-
tionism, which explores the processes of interaction
between people’s social roles and behaviours (Denzin
1989). In grounded theory, the settings in which people
live and where everyday events occur are an important
part of the data (Hutchinson 1993, Holloway & Wheeler 1996).

Within the context of the overall study, a substantive theory emerged to explain the strategies that nurses used to enable clients who are experiencing an early episode of psychotic illness to regain a state of well-being. This paper relates only to the processes that nurses engage in to advance client self-determination.

Sampling

The study took place in the community, in regional and rural New South Wales, Australia. The participants included young adult clients with schizophrenia and community mental health nurses who worked in three community mental health centres. Purposive sampling (Patton 1990) informed data collection at first. As initial data were collected and analysed, further decisions about sampling participants, settings and types of data collected were guided by the emerging substantive theory (Glaser 1978). Theoretical sampling took place when the researcher collected new data to compare emerging categories (e.g. advancing self-determination) that were related to the evolving theory (Strauss & Corbin 1990). It occurred as the researcher identified emerging categories, and involved analysing, checking, filling out categories and, where appropriate, returning to the field to extend categories (Charmaz 1990). Theoretical saturation of the main concepts identified in the data determined the number of participants and time spent in the field (Glaser 1978, Strauss & Corbin 1990, Benton 1993, Hutchinson 1993, Olshansky 1996).

Data collection

Data collection and analysis took place concurrently, in accordance with the grounded theory approach. This provided valuable sources of data, which were then used in a painstaking model of analysis, dense and precise enough for a theory to be grounded. Nine clients, five men and four women, were interviewed (one was interviewed twice), six of whom were also observed. Their ages ranged from 18 to 30 years. None was currently in paid employment; most had never been in paid employment. All participants lived in the community, most in their family homes. Each was prescribed regular antipsychotic medications. Twenty-four nurses were interviewed (two were interviewed twice), six of whom were also observed. There was equal gender representation of nurses. All but two were aged between 30 and 49 years. Their average clinical experience was 12.8 years, with a range of 3–30 years.

The face-to-face interviews were carried out in a relaxed and private environment and were tape-recorded. Their format was unstructured and conversational, loosely guided by aides-memoires, which are open-ended, flexible guides to topics that might be covered in interviews (Burgess 1984). For instance, nurse participants were asked, ‘How do you facilitate clients towards self-determination?’ In total, 44 interviews were held, each lasting 60–90 min. The interviews allowed the informants to describe their experiences in their own way (Patton 1990, Porter 1996), about how nurses promoted client self-determination. Nonparticipant observations were used to generate theoretical accuracy, grounded in the social reality of participants’ everyday lives (Jorgensen 1989). The researcher observed nurse participants at work in community mental health centres and accompanied them during visits to clients’ homes, observing and listening to interactions between nurses and clients. In total, the researcher spent approximately 55 hours observing interactions. Theoretical saturation was achieved when the main concepts that were identified began to recur in the data.

Data analysis

Tape-recorded and hand-written field notes and memos were transcribed following each episode of fieldwork. Pseudonyms were used throughout. The transcribed data were coded and analysed using the steps outlined by Strauss & Corbin (1990, 1998) The coding process commenced with open coding. Conceptual labels were then linked into more abstract categories, and the properties and dimensions of the categories were identified. Axial coding followed, where the data were put back together in a different way, through categorizing the data and making links between categories and subcategories (Carpenter 1995, Irurita 1996). Finally, selective coding took place, with the aim of identifying a core or overarching category (Glaser 1978). It is important to note that this procedure occurred within the context of the larger study, but is implicit in the way the findings have been presented in this paper.

Ethical considerations

The relevant ethics committees gave approval for this study. Five key ethical issues were respected: ensuring informed, voluntary consent; respecting the right to withdraw at any time; maintaining privacy, anonymity and confidentiality; avoiding harm to participants; and making it clear to participants that alleged unethical and illegal conduct would be reported to the appropriate authority.

Findings

Based on grounded theory analysis, two categories emerged from the data as central themes which elucidate how nurses
set about the process of advancing self-determination: educating and fostering self-control.

Educating
From the nurses’ perspective, one aspect of advancing self-determination is educating, which necessitates informing and equipping clients to facilitate recovery to wellness. The intent of educating is to increase knowledge and understanding, to change attitudes and behaviours that are not conducive to advancing self-determination, and reinforce those that support the concept. As such, educating is integral to the promotion of wellness. Two main strategies are used in the process of educating: knowing how and knowing what.

Knowing how
Intrinsic to the technique of educating is knowing how to carry out the process of educating. The data provide a number of guiding principles for this process. The first, and most important, principle is that education takes place within the context of a developing relationship characterized by a mutual alliance. This entails using an open and participatory approach, an equitable approach, rather than a nurse-centred, expert-led way of providing education:

It is important not to impart too much information at the beginning. They don’t take it in . . . I would generally look at doing things very slowly, and being available . . . so that the family see me as a resource person (Phillip – nurse).

The data indicate that education cannot be imposed but should be offered when clients are ready to receive it. This activity involves establishing recipients’ level of knowledge and understanding, as what is suitable in one situation may be inappropriate in another. Consideration is also given to the context in which education takes place. It is clear that when clients are preoccupied with what they regard as a crisis in their lives, it is appropriate to leave more detailed education to later as retention of information is likely to be compromised. In the immediate crisis, explanations that are structured, straightforward and devoid of technical jargon are more readily understood. When the situation is more stable, the level and complexity of education can be increased. Eugene illustrates how the process can be assisted with the use of medical analogies to explain and attempt to normalize mental illness, and to emphasize that the illness is treatable:

I try to normalize the experience, by trying to make comparisons with schizophrenia and something like diabetes. ‘If you keep taking the medication, it keeps you in control, just like a diabetic who takes medication to keep them in control. A diabetic is allergic to chocolate, and that interferes with their blood sugar levels.’ Somebody with mental illness is allergic to illicit substances. ‘It’s a bit like putting your mental illness on a bankcard. You have a really good time now, it reduces the side-effects of medications and makes it really easy; reduces the illness as well. But the consequences are, there’s a long-term pay back.’

Knowing what
The process of knowing what involves dealing with issues that enable clients to increase their knowledge and understanding of the illness. This includes helping to increase their understanding of what is occurring, explaining care and treatment issues, and enhancing clients’ transition to wellness. It is evident that people have a need to know what is happening to them – they want a diagnosis. In giving information and dispelling myths about the illness, nurses claim they avoid using labels, such as schizophrenia, until a definite diagnosis is made. Instead, they prefer to discuss how to improve the immediate situation and try to avoid recurrence of the illness, as Geraldine shows:

Initially, . . . I tentatively talk about what the symptoms can mean. It’s like when a woman goes to the doctor and finds out she’s got a tumour in her breast. The doctor does not immediately say, ‘Well, you could die from this, dear.’ He just doesn’t do it that way. He talks about the things you can do and later on when they don’t work, he might talk then, about what the prognosis is.

The strategy of educating focuses on helping clients cope with the illness and deal with the sense of loss. Jeff, a client, emphasizes how he assesses the influence of vulnerability-stress as a major trigger for mental illness. This involves assessing lifestyle and identifying stressful events, and heightening clients’ awareness of the need to avoid such situations:

The first one occurred when my father was dying of cancer and that was pretty stressful at the time. That probably initiated my first episode. In my second episode, I stopped taking medication about a year after I recovered the first time . . . I also started my Master’s [degree] course, and I was really worried about passing and getting a job, and the money aspect of not running out of cash. Those stresses combined and, sort of, put me into another episode.

In addition to avoiding stressful events, participants claim that it is necessary to examine how clients usually cope with stressors, so they can attempt to harness these approaches to help clients deal with these situations. They also maintain that it is important for nurses to be accessible, listen, offer support, and provide assistance (McCann 1999).
An important element in relatives’ involvement with clients, apparent in the interviews and observations, is being able to recognize the effect of family interactions on clients’ well-being. A home environment that is friendly and supportive provides a valuable framework for promoting wellness, but the issue of relatives’ interactions needs to be seen in the light of other influences. Attempts to provide a supportive home environment can be undermined if, secondary to mental illness, relatives’ sleep is disrupted, inadequate external support is received, limited or no respite is available, and financial hardship occurs. Scarce opportunities for respite mean that caregiver burden is increased and a supportive home can, unintentionally, become an environment of high expressed emotion. For instance, when Martin experienced an acute psychotic episode, his parents locked him in his bedroom because they had limited support and understanding of his illness.

Another aspect of educating involves an emphasis on recognizing relapse signatures, in order to intervene early and avoid the possibility of a complete relapse taking place. Jacqueline illustrates her personal experience of relapse signature: ‘What I do notice is that I mostly do not sleep properly when I am becoming unwell. I also get a bit bizarre nature.’ Similarly, Teresa explains the emphasis she places on early detection of, and intervention with, my thought patterns. ‘What I do notice is that I mostly do not sleep properly when I am becoming unwell. I also get a bit bizarre with my thought patterns.’

Fostering self-control necessitates changing the balance in decision making and regain self-control are intrinsic to clients’ well-being. It takes place within the context of a trusting relationship and is dependent on a thorough and ongoing assessment of readiness to take self-control (McCann 1999). There is an association between clients’ taking control and their transition to wellness.

I believe it’s important that they have control of their own lives. Otherwise, you end up with them being institutionalized, again. But you are doing it in the community, this time. It’s all about creating independence for them, not dependence on me (Rachel – nurse).

Fostering self-control is a process that takes place throughout the episode of care. The activity is premised on nurses and clients believing that taking an active part in decision making and regaining self-control are intrinsic to clients’ well-being. It takes place within the context of a trusting relationship and is dependent on a thorough and ongoing assessment of readiness to take self-control (McCann 1999). There is an association between clients’ taking control and their transition to wellness.

Interviewer: Is there anything else that helps you stay well?

Martin (client): When I am in control, in control of myself, in control of the things I do. I would like to be in control of anything that I do.

Implicit in clients being in control is the need for them to recognize that they have a mental illness. Clients are better positioned to get well when they recognize that the illness is the problem, rather than seeing themselves as the problem. Individuals who are able to externalize the illness are more receptive to nurses’ efforts to foster self-control and enhance recovery. In contrast, clients who internalize the illness and blame themselves for their predicament are less amenable to nurses’ attempts to foster and expedite care processes:

I try to get them to externalize it, to see if I can get them to see their illness as problems rather than being part of them. So they can look at that particular problem and see some solutions to it, rather than saying this my personality, now . . . it just seems to work that way (Geraldine – nurse).

Nurses use two main strategies to foster client self-control: changing the balance, and enabling control.

Changing the balance

Fostering self-control necessitates changing the balance in decision making and control of care, and this involves nurses examining their perception of clients’ roles in caring relationships. If nurses regard themselves as the ‘expert’ in the caring relationship, then they are unlikely to accept client participation in decision making. At times the balance of decision making resides more with nurses, especially during the early part of the acute episode, although fostering self-control underpins their decisions. As clients are increasingly enabled, the balance of decision making shifts progressively towards self-control. The process also requires nurses to know when it is appropriate to move the balance of decision making and responsibility to clients.
Determining the level of clients’ understanding is the basis of ongoing assessment, premised on the belief that it is in clients’ interest to assume control:

I tend to work in a way that puts more responsibility back on the client for their health. That sometimes means allowing them to do what, in my opinion, is not in their best interest. I found that quite often, pushing people into behaving the way you want them to behave does not actually enhance their health (Phillip – nurse).

**Enabling control**

The process of enabling control is brought about by education, so clients are aware of the implications of their illness and their role in regaining a state of well-being. If clients are educated, they are well placed to assume self-determination. Enabling control is more than education. It encompasses nurses, within the context of a trusting relationship, consciously and ingeniously involving clients in decision making throughout the episode of care. This calls for them to consult, to seek their opinion, listen to, work together, and encourage. The issue of control is central to advancing self-determination and also has implications for relatives. In this context, consideration needs to be given to counselling relatives against being over protective of clients. For instance, Kieran recounted how he spoke to Martin’s parents about the importance of allowing him to lead his own life.

**Discussion**

In advancing self-determination, these nurses seek to preserve, enhance and promote client self-control and decision making. The process shows how nurses seek to maintain, increase and uphold client self-control and decision making, and why it is an indispensable factor that helps bring about transition to wellness.

It is evident in the data that nurses regard education as essential for clients. Educating is consistent with supporting the psychological need for competence. To be self-determining, clients must be educated about how to deal with the illness-related issues that confront them, otherwise these issues will control their lives (Deci & Ryan 1985). Those who are educated are better equipped to take control of their lives than those with little or no education. Education as a means of imparting information about the illness is useful, but more important is the process of educating and the underlying assumptions that inform it. Nurses in the study used two key models of education: deficit and collaborative interactional. A deficit model is premised on the assumption that clients have inadequate knowledge about schizophrenia, and this contributes to behaviour that undermines their well-being (Tarrier & Barrowclough 1986). By improving knowledge through mainly professional-centred education, it is assumed that improvements in health-related behaviours will take place. For example, the model can be applied to reduce the level of expressed emotion in relatives. The model incorrectly assumes that an improvement in knowledge about high expressed emotion will correct behavioural deficits. Adherence to the deficit model reflects nurses’ limited knowledge about client education. Activity concentrates mainly on clients’ lifestyle, but this overlooks the broader contextual determinants that impinge on promoting wellness, such as inadequate provision of services, political factors, absence of paid work and poverty (McKeown 1979, Townsend et al. 1992). Education can be used as an important medium for empowering, but it can also be disempowering (Freire 1972). There is an implicit danger of victim blaming when education focuses almost exclusively on clients’ behaviour. Ill health and the broader problems of inequality may be wrongly attributed to an individual’s lifestyle (Kingsley 1994, Robinson & Hill 1998), and this concept of blame can be reflected in the behaviours of nurses. Thus, the cause and remedy for ill health is located in the individual. Although the individualistic approach emphasizes participation and choice, it is premised on an ideology that considers clients responsible for their own well-being, in both illness and wellness (Williams 1994, Rush 1997, Johnson 2001).

Other nurse participants use a collaborative interactional model of education. This model acknowledges the influence of the subjective, experiential (phenomenological) perspective as well as the medically informed, objective view of schizophrenia. This approach postulates that educational content and strategies influence clients and, as a result, the contextual influences on health must be considered (Tarrier & Barrowclough 1986). A collaborative interactional model, conceived through the perspective of clients’ beliefs and experiences of schizophrenia, is more beneficial than a deficit approach (Brooker et al. 1992, Kalia et al. 1995), because individuals commonly adopt lay models of sickness to understand and come to terms with their ill health (Helman 1981).

It is evident that fostering self-control is an integral part of the process of promoting wellness (Valimaki & Leino-Kilpi 1998). In the absence of control, client self-determination will be merely symbolic. The progression to wellness can occur in the absence of actual control, but its absence fosters dependence, powerlessness, and undermines client autonomy. In these circumstances, it is unlikely that clients will achieve their potential for wellness, as self-determination is an integral part of wellness.

At the heart of the process of advancing self-determination is recognition that an unequal relationship...
exists between clients and nurses, and as a result of their precarious situation, clients are in a relatively limited position to take part in self-determination. The underlying assumption by nurses in advancing self-determination is that clients will choose wellness-focused behaviour. It may be viewed as contrary to nurses’ intentions to enhance transition to wellness if clients choose not to participate in wellness-related behaviour, because of various contextual determinants. The data reveal that there are limits to client self-determination. Because the degree of client participation, power and self-control varies, nurses may use a top-down approach to promote wellness. In this situation, it is appropriate to regard this relationship as an alliance, rather than a partnership, because of the power differential between nurses and clients (Barker 1999).

### Study limitations

The results are context bound to the participants and the setting in which the study took place (Duffy 1985, Lincoln & Guba 1985, Stern 1985, Hutchinson 1993). Even though generalizability is not an essential requirement of this type of research (Sandelowski 1993), the findings can be verified (Corbin & Strauss 1990), and they provide an important guide for nurses in other clinical settings.

The study was guided by Lincoln & Guba’s (1985) four criteria for assessing rigour in qualitative studies: credibility, dependability, transferability and confirmability. Researcher bias was addressed by self-awareness of mindset or being reflexive (Porter 1996, Bent 1999), or what Van Maanen (1988, pp. 73–100) referred to as adopting a confessional style. This involved:

1. making explicit the theoretical perspective being used;
2. examining preconceived assumptions and expectations about the phenomenon under study;
3. reflecting on these assumptions and expectations throughout the various stages of the study through the use of a daily diary.

### Implications

The findings have implications for education, clinical practice and research. Educationally, greater emphasis needs to be placed on equipping nurses to use a collaborative interactional model of client education. Clinically, nurses need to reflect on the type of relationship that they should have with clients. A relationship that is conducive to fostering self-control is premised on nurses recognizing and supporting clients to take an active part in decision making and regaining self-control. Finally, there is a need for further research into the promotion of self-determination with clients in inpatient settings and those with other psychotic illnesses.

### Conclusion

Advancing self-determination is the phase in which nurses place emphasis on the processes of educating and fostering self-control in order to promote wellness. The phase is, at times, tortuous, and the level of self-determination achieved is influenced by a number of factors. Two factors underpin advancing self-determination. There needs to be a mutual, trusting relationship between nurses and clients. In the absence of this type of relationship, it is difficult for the advancement of self-determination to eventuate. Related to this, there is a need for nurses to assess their discourse of care. What is required is a discourse that recognizes the value of an alliance, which provides the basis for advancing self-determination. Implicit in both is recognition that self-determination is central to the process of promoting wellness. Prescribing self-determination is not the same as supporting it.

### Acknowledgments

Thanks to the Nurses Registration Board of New South Wales, Australia, for providing a grant to carry out the fieldwork for the study; and to Professor Helen Baker, School of Nursing and Midwifery, Victoria University, for her support with the project.

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