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Being active supports client control over health care

ABSTRACT

The purpose of this study was to identify how healthcare clients achieve and maintain a sense of control over their health. The literature review conducted refers to: (i) key definitions of control, (ii) locus of control, and (iii) control and wellbeing. Participants with a range of acute and chronic health conditions and who had been hospitalised at some point were selected for the study. Symbolic interactionism (Blumer, 1969) and modified grounded theory of Strauss & Corbin (1998) provided the frameworks for this study. During the six month study period, data were collected from sixty participants and included interviews, participant observation, reviewing participants' records (nursing care plans, nursing notes and case histories), the nursing units' philosophy, organisational charts, policies and procedures, annual reports, consumer brochures and any other relevant information sources. Findings from the study indicated that participants moved from feeling vulnerable to having a sense of control through to being purposefully active. Vulnerability was associated with: (i) having limited choices in respect to their health, (ii) lacking adequate health information to make choices, (iii) being ignored by health providers with respect to their needs, and (iv) lacking friend/family supports. Purposefully activating was associated with three major categories: (i) reflecting, (ii) being self-determiningly involved and (iii) normalising. Findings from this study could be used by health care clients who want a sense of control over their health care, and also by health care providers who wish to support clients in the healthcare process.

KEY WORDS

client control, grounded theory, symbolic interactionism, the active client.

Received 16 April 2003

Accepted 24 March 2004



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INTRODUCTION

The purpose of this study was to identify how health care clients achieve and maintain a sense of control over their health care. There have been a series of quantitative studies, particularly the seminal works of Seligman (1975, 1992) and Skinner (1996) on the nature of control. What appears to be lacking is a qualitative study that explores the processes that health care recipients use to gain and maintain a sense of control over their health care. The aim of this current study sets is to verify that identified shortfall in the literature by examining how health care clients achieve and maintain a sense of control over their health care. The psychological literature was reviewed and will be discussed in relation to the findings of the study. Also included are the methods used to answer the research question, and the findings and implications of the study.

LITERATURE REVIEW

There have been numerous studies published in the psychological literature over the last 50 years on the topic of control. The literature included the personal sense of control, locus of control, decisional control, predictive control, proxy control and the experience of control (Skinner, 1996). This review briefly covered three areas: (i) key definitions on control, (ii) locus of control, and (iii) control and general well being. Skinner (1996) and Seligman's (1975) provided the key perspectives on control. Skinner (1996) viewed control as an individual's capacity to prevent or produce a desired outcome. Seligman's (1975) seminal work on helplessness found that uncontrollable events are those where the outcome is not related to the individual's actions. A gap between the person's actions and the outcome resulted in stress and anxiety initially and later helplessness and depression. Individuals experience a lack of control when they sense that their responses do not make a difference (Abramson et al. 1978). A person's sense of competence is more seri-

ously undermined when he or she cannot bring about the desired outcome, rather than when the outcome is uncontrollable, that is, no one can cause the desired outcome. As people achieve goals and master both the internal and external environments and make the unfamiliar become familiar, they experience a sense of control.

Early seminal works on the locus of control have stemmed from Rotter (1954, 1966, 1975) and Social Learning Theory. According to this theory, people with an internal locus of control believe that their own behaviour determines their control over the situation, whereas people with an external locus of control, believe that they cannot predict what happens to them because they are dependent on others for what happens.

Over the last three decades, there have been many psychological studies conducted in the area of control and most studies agree (Averill, 1973; Miller, 1979; Thompson, 1981; Skinner, 1996; Marks, 1998) that the experience of control is usually beneficial. Some situations do exist where control is negative (Burish et al. 1984). Some studies (Burish et al. 1984; Wallston, 1992; Marks, 1998) have found that during serious illness, control may be detrimental and an external locus of control an advantage.

With the increased level of chronic disease and the need to contribute to and live with long-term treatment regimes, it is important that everyone who wants control over their health care should be offered the opportunity to be in control (Marks, 1998). There have been a series of quantitative studies, particularly the seminal works of Seligman (1975, 1992), and Skinner (1996) on the nature of control. What appears to be lacking is a qualitative study that explores the processes that health care recipients use to gain and maintain a sense of control over their health care. The aim of this current study is to verify that identified shortfall in the literature by examining how health care clients

achieve and maintain a sense of control over their health care.

METHODS

The symbolic interactionist perspective of Blumer (1969), together with Strauss and Corbin's (1998) modified grounded theory provided the frameworks for this study. This included participant reflections and interpretations, and their construction and reconstruction of their perceptions of control, and reflections on the socialising process. Given the importance of this self-reflective venture and the importance of meaning for the individual, a symbolic interactionist perspective found to be a most useful approach. Symbolic interactionism (Mead, 1934; Blumer, 1969; Bowers, 1988) is a theory of social interaction and behaviours concerned with the self, the world and social action. Social action is formulated by the combined purposeful actions of people who use shared symbols and form the social structure and pattern of the social world. According to this theory society is viewed as the outcome of individuals' responses and only exists through individuals who construct it. Society is also a process that continuously changes in response to the individual's use of shared symbols (Smith & Manning, 1982; Bowers, 1988). Symbolic interactionism supports exploring the natural setting and human beings in respect to their self-reflective interpretation of their social and historical context. In these ways symbolic interactionism allows the inquirer to explore the research participant's knowledge of themselves through their human social world and the behaviour that is expressed in social interaction.

Grounded theory method supports symbolic interactionism because it is a method of analysis that allows one to examine the interactive nature of events (Strauss & Corbin, 1998). Grounded theory method provides for interpretations of actions and procedures to identify social processes. In this study, grounded theory supported the development of a model of par-

ticipant control over their health care. It provided the procedures to collect and interpret findings to generate a model of social psychological processes. Grounded theory method aims to identify the issues from the research participant's perspective and generate a model that explains the social processes involved (Stern, 1985).

This study utilised the techniques first identified by Glaser and Strauss (1967) of: theoretical sampling; constant comparative data analysis; theoretical sensitivity; memo writing; identification of a core category; and theoretical saturation. Apart from these fundamental strategies other techniques used in this study developed by Strauss and Corbin (Anells, 1997:178) were the grounding of theory upon data through data theory interplay, the making of constant comparisons, the asking of theoretically oriented questions, theoretical coding, and the development of theory. This method suited the aims of this research study because it focused on social processes, structures and interactions and had a relativist (views the social world as constructed) rather than realist (absolutes that have to be found) perspective (Stern, 1985; Strauss & Corbin 1998). This contemporary mode developed an inductive grounded theory that could inform the inquirer in respect to interactions and social conditions in situations of interest.

ETHICS

Ethics approval was gained from the related university and the university's approval was accepted by the relevant public and private health services. Prospective participants were accessed through an intermediary (who had no particular interest in the study), usually a nurse (who was not providing direct nursing care to the client), or recruited through information flyers which had been placed at various central points in the health services. Those who were interested in participating in the project completed an expression of interest form. Only

those people who met the inclusion criteria were accepted into the study.

The inclusion criteria included that individuals volunteered for the study, were aged over twenty one years, could understand the nature of the issues involved, and make judgments and articulate their position. With this particular criteria, competency to consent was not an issue (Archbold, 1986). Potential participants were given a verbal explanation of the nature of the study, as well as written information. All those who agreed to participate in the study were required to sign a consent form. Written consent included consent to be interviewed and audio taped, and/or to be observed for a period of time. Interview locations were negotiated with each participant to achieve maximum privacy. Participants were informed that they could withdraw their consent at any time or ask for any part of the interview to be deleted, without having to give a reason. No participant took advantage of this opportunity. Participants were also informed in writing and verbally that refusal to participate in the study would in no way adversely affect their treatment and care. All data were treated as confidential and kept under lock and key. Anonymity was maintained by not using individual names of health services or clients. Participants' names were coded and the codes were placed on tapes, field notes, reflections, memos or transcribed material. Transcriptions were stored on computer and protected by a password, tape recordings, field notes and memos were placed in a locked filing cabinet at the researcher's place of work. The experiences of each participant were merged into the analysis of the field data so that no one participant experience could be identified. Care was taken when writing the report to omit details such as diagnosis and location to avoid connections to particular individuals. Permission was obtained from participants to disseminate the findings of the study through journals and conferences for health professional and consumers.

SAMPLING

Participants were selected from a breadth and depth of available people initially by purposive sampling (Patton, 1990) and thereafter according to theoretical sampling (Glaser & Strauss, 1967). Purposeful sampling is a strategy to select subjects who are considered typical of the population (Denzin & Lincoln, 1994). In this study participants were initially selected on the basis that they had experienced an acute or chronic illness and a hospitalisation. Theoretical sampling offers an opportunity to sample "on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990: 176). This perspective drives the development of categories, their properties and processes. In order to obtain a wide range of experiences participants were selected who had experienced a sense of control, a lack of control, and both a desire to have and not have a sense of control. Participants were sought from a range of settings, ages and both genders, although more females expressed an interest in being part of the study than males. This strategy enabled comparisons across groups and obtained sufficient depth to begin to understand the contexts and meanings of the participants' experiences. Some participants were targeted to pursue specific issues as they emerged according to theoretical need and the need for variation. This selection strategy permitted those people with a range of experiences to be incorporated in the study. Individual group settings were selected according to where "the processes being studied are most likely to occur ... A focus on negative cases is a key feature of this process" (Denzin & Lincoln, 1994: 202).

Throughout the study, documents pertaining to participants' records (nursing care plans, nursing notes and case histories), the nursing units philosophy and objectives, organisational charts, policies and procedures, annual reports, consumer brochures and information sources were used as sources of data. Data were also

collected using participant observation and individual interviews. Participant observation was utilised in the inpatient facilities (two public and one private hospital) and lasted for six months. During this period sixty clients participated in the study resulting in over six hundred pages of field notes. Twenty-two clients from the inpatient/outpatients, renal dialysis and community settings were interviewed in-depth twice. If these nine were men and thirteen were women. Their ages ranged from 25 to 78 years, with an average age of 53 years.

DATA ANALYSIS

Data from interviews and participant observation, documentation and literature were analysed through a process of open coding, category coding, theoretical coding and the development of the core category or process. This was achieved through a process of coding data and comparing and contrasting codes, asking questions, grouping the codes into categories and integrating categories and their properties into a theory. Data were compared from one area with data from another area, and commonalities and differences across interviews and participant observation were identified. Through this process maximum variation, diversity and negative cases were pursued. Through a process of writing memos, further theoretical sampling (according to emerging theory) and theoretical sensitivity, a diagram of the categories and their relationships emerged.

FINDINGS: BEING ACTIVE SUPPORTS CLIENT CONTROL

The core problem experienced by participants in respect to a sense of control when interfacing with the health service was a sense of vulnerability. The core process participants used to address their sense of vulnerability and achieve and maintain a sense of control over the situation was purposefully activating.

Health care clients have a sense of vulnerability associated with the illness and/or health

care service experience. Feelings of vulnerability are associated with: (i) having limited choices in respect to their health, (ii) lacking adequate health information to make choices, (iii) being ignored by health providers in respect to their needs, and (iv) lacking friend/family supports.

Having limited choices in respect to their health

Having limited choices in respect to health was illustrated by this participant who expressed her anger at the extent of physical trauma, pain, deteriorating health and lack of recognition by others whilst having to deal with treatment for renal disease:

What happened, when they put the fistula in, the next day or so they come and said "oh we've put it in upside down, we've got to put it back in again, you've got to go back (to theatre) again". So I went back in again and then a great big blood clot three weeks I laid there in agony, each doctor, oh yeah, and just walked on, you know. And I was just getting angrier and angrier. (P10)

Lacking adequate health information

'Needing to know' was illustrated by this participant speaking of her sense of vulnerability and exclusion associated with a lack of confidence in nurses and doctors, which related to health provider's failure to communicate adequate information about themselves, what they were doing to assist the client and their capacity to manage her health problem:

Well I was really out of control 'cause I didn't know what was happening. Well I sort of knew it was asthma, at first I thought it was just asthma, but I couldn't control the asthma especially the next day when I got worse. I just, there was nothing I could do about it. Then I came back here and to the medical ward and I just, you know, I suppose I got

really depressed because I didn't know what was going on, I was scared to be back in the medical ward because I wasn't quite sure if they knew how to care for me. I kept saying are you sure I shouldn't be back in the intensive care unit? (P1)

me yet, don't sort of make me an invalid or on death's doorstep possibly yet'. (P13)

Being ignored

This woman, hospitalised for many weeks with a critical illness, displayed the feelings of vulnerability associated with the need for more sensitive attention that incorporated hope of recovery. She found that the only time that she was listened to by nurses was when she was visibly upset. She also believed in the need to be included in her plan of care because she did not like decisions being made about her when she was capable of making decisions herself:

Ah, so sad isn't it, that you have to get so anxious and afraid that you cry and then they [nurses] might turn around and listen to you. Then again I suppose independence had gone and I was still trying to act like 'hey I'm a normal girl and you can't take it away from

PURPOSEFULLY ACTIVATING

Findings, in the study reported here revealed that, when the study participants felt vulnerable, they might withdraw and leave all decisions to health care providers. Such withdrawal might be active or passive. Those who passively withdrew simply waited for the health care provider to tell them what to do, those who actively withdrew, were usually waiting for another more appropriate time to act. 'Finding hope' was a central factor that allowed the person to move from withdrawing to being active. Being active had three major features: (i) reflecting, (ii) being self-determiningly involved and (iii) normalising. The figure below demonstrates this activating process.

This model is called purposefully activating. The person needs to be active and goal directed. Categories of purposefully activating include: (i) reflecting, (ii) being self-determiningly involved and (iii) normalising.

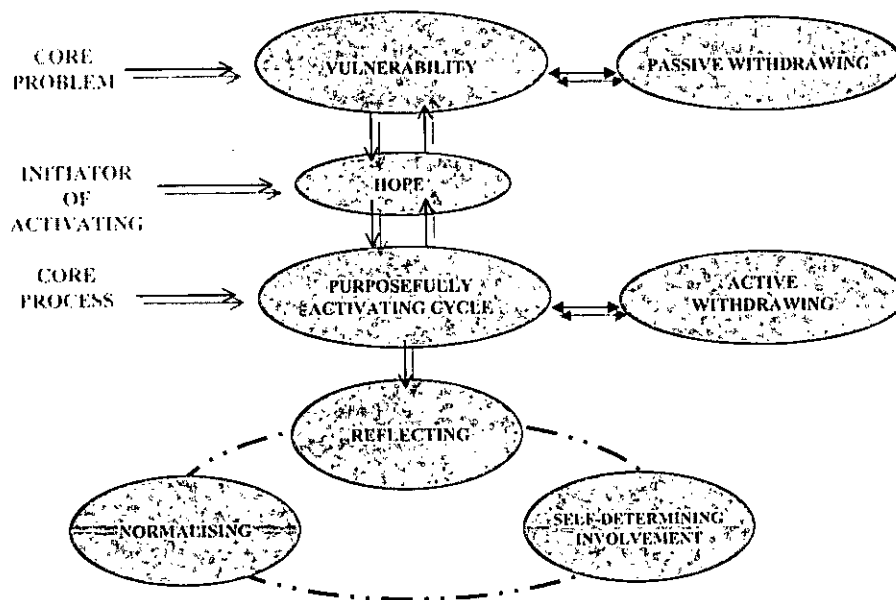


FIGURE 1: The model of purposefully activating

Reflecting

'Reflecting' is a human characteristic (Taylor, 2003; Bray, 2000) and when conducted in a systemised way, may not only be a way of thinking deeply about a situation but may also provide further clarification of issues and be a source of personal knowing for clients. During this phase, individuals try to make sense of the situation. They do this by reflecting inward and outward, by thinking, analysing, evaluating, and considering previous experience/s. They reflect on the nature of the health disruption in relation to current circumstances: questioning the current situation and exploring their thoughts and feelings on the matter. As a consequence of this reflecting, they have an opportunity to assess their position while considering acceptable short-term health goals and ways to work towards achieving them. As an example, one participant tried to make sense of her transfer from a medical ward to an intensive care unit. Although previously hospitalised for asthma, the woman had never previously needed to be admitted to an intensive care unit:

And I wondered, what does this mean? I haven't really ever had to go to intensive care in my whole life. (P1)

Reflecting was part of this next woman's experience of childbirth as she tried to make sense of the situation. Reflecting on past experiences of childbirth gave her a benchmark to measure her progress and plan future strategies. She tried to work out how she could have made better arrangements that would have prevented her present dilemma:

The fact that I hadn't dilated very much. Babies can't come down if they can't get out, you've got to be open-so-they can, and to be open in my mind was to be allowing it to all happen, I don't dilate very readily, maybe I don't let myself. You search yourself, well I mean this is after I'd had the drip, I had my

membranes ruptured, I'd had gel the night before, at midnight and four in the morning and eight o'clock that same morning, the gel actually, so three lots of gel, plus the membranes ruptured, plus the drip and I'm still only 1 cm dilated, God. I was thinking I should have had a caesarean, I should have asked for an elective Caesar and if I ever was pregnant again I would no matter what anyone, any doctor says. The only thing that was different about it was it wasn't as long, my son was something like twenty eight hours, this [daughter] was eleven and a half hours, so it was half. When I tell that to some people they say well that's half isn't it, half is still bloody bad. Half is not good. I'll tell you what half is, half is elective caesarean in the future, if there are any, but not that we're really planning any more. (P5)

Another woman tried to recall the period when she was quite unexpectedly critically ill, vulnerable and dependent. This reflection provided her with a basis to make future plans and was a means of comparing her various experiences of vulnerability with each other. Even weeks after an acute phase of an illness, this participant was still reflecting on her experience and associated behaviour trying to recall what happened so that she could accommodate or make sense of what happened and how she behaved:

... it's interesting, I got admitted to the city hospital on the second of June and they did the surgery on the fifth and I can vaguely remember procedures and tests that I had done, but I can't remember things. People tell me now of little things and then I recall them but I can't remember everything in detail and that's a curious experience for me. In terms of during the hallucinatory period, I don't think I ever thought to myself you know 'this is the drugs that are affecting me' because it was so unknown, because the treatment that I had was not expected for

anybody. The surgeon and nursing staff had ended up taking a path that wasn't intended because the intracranial pressure was not going down. (P13)

This particular participant went to the extent of obtaining a copy of her medical and nursing notes so that she could try to understand what had happened to her during her period of unconsciousness and psychosis.

Self-determiningly involved

The second phase, self-determining involvement, either follows or occurs simultaneously with reflection and requires the client to be actively exploring for resources and support. The subcategories of self-determining involvement include (i) working knowledge, (ii) seeking resources, (iii) health provider inclusivity and (iv) fortifying family and friends.

One woman's search for health services that suited her needs is illustrated thus:

The right answers, that you understand what you're being told. I mean I suppose the feeling of being out of control or not good control if you don't know who to see about something, you don't, you're not sure which specialist to choose. There is nothing on the internet about their qualifications and experience. (P5)

This next woman appreciated the nurse's presence, her availability and attempts to keep her informed about what was happening by seeking further explanations from doctors. She asked for more inclusion and explanation by medical staff:

I suppose mainly the reassurance and the, there was a nurse who really spent some time and sat down and had a really good talk to me and told me what's happening. She asked me about my concerns and what I wanted and she also asked the doctor to come and talk to me. (P1)

The presence of friends and family was said to provide support central to the activating process:

Someone from work, as well as my wife, has been here everyday to see how I'm going. It's great to know they care. (P2)

I saw people I knew once a week, on Sunday. My daughter brought my mum down every Sunday and that was the only day, I used to look forward to that day so much I said to her when I came back, I just needed somebody to understand, and she did. Just her concern and knowledge helped me a terrible lot. (P10)

During the process of 'purposefully activating', clients may gain support from health providers or from family and friends. Family and friends may play a central role in health care because of their knowledge of the client's wishes and their knowledge of them as people (ie. how clients like to live) and this can be very helpful in assisting clients meet their goals. While the client is in hospital, carers may also learn the skills and knowledge required to care for the client at home.

At the heart of 'self-determining involvement' is an acceptance of one's own authority and capability to bring about a change in the health situation, or to have the support of others who can. This includes a preparedness to own one's health state and to take action to improve the situation. During the 'self-determining involvement' stage, individuals may choose to passively or actively withdraw and live with vulnerability or choose to continue to be active. 'Purposeful activity' processes individuals into the next phase where they attempt to meet their goals by trying to return to living life as close to their previous way of living that is possible.

Normalising

During the last phase, the outcome of activating

behaviours – normalising – the individual is getting healthier or living with health disruption but adjusting and normalising; living a life as close as possible to their previous way of living. This includes decreasing vulnerability and increasing control over health and goal achievement. This next participant, an older women, wanted to go to the ocean beach again because in her mind, this is as close to normal as she could expect to get:

I can't get up (laughs) I'd like to go down and sit on the beach but I know I can't get up off the floor yet. I've got to have some something still to just to lever me up. It's a goal. And I asked the doctor about, because I always loved going in the water, could I go in the water. He said well not the pool, so I imagine I wouldn't be able to go in the pools, I thought well if I strapped it (cannula) up with some waterproof stuff in the summer and then when I come out have some sterilising stuff to wash it so that no sand or anything. Just go but not the surf, I wouldn't go in the surf. So they're things I definitely want to try and do this year. (P10)

Attempting normalcy may occur whilst coping with an abnormal treatment experience or by recasting goals:

But also when I came in here, everybody said you make dialysis part of your life. I can't remember which way they put it, so that you don't sort of build your life around it, you still have a life and it sort of comes as secondary. (P7)

Um, I understand now that things will never be the same, but I think that I would like to -- aim-to-get-back-to-as-close-as-where I was before all this happened. (P13)

Normalising for some involved being able to contribute – for example one woman spoke of

visiting a nursing home as her contribution – and central to normalizing was regaining control, although:

There are two types of control, one is better than the other, control of self when I actually dictate what I want, having a say in being cared for, and self-control when I actually fit into what others want. Control of self is better. (P15)

DISCUSSION

A few nursing theorists have proposed theories that incorporate the concept of vulnerability. In Australia, Irurita (1996) proposed a theory of preserving integrity. This grounded theory had, as its core problem, vulnerability. Irurita (1996:271) acknowledged the need to develop this concept further. In her study, vulnerability was seen to be closely associated with health disruption, equitable relationships between nurses and clients, and the age of the client, and the core process for addressing vulnerability was preserving integrity. Lawler (1991) another Australian nurse theorist commented on client vulnerability. She links the concept to uncertain and often painful illness and treatment experience and the unfamiliar hospital environment or surroundings (Lawler, 1991). Only a few North American nurse theorists refer to vulnerability as a concept. Lessick et al. (1992) proposed a conceptual model of vulnerability for perinatal and neonatal nursing. This model proposed an emphasis on vulnerability rather than illness. It is concerned with the biological, psychological, social and cognitive aspects of the client in relation to the environment and how they influence their vulnerability. An early theorist Weidenback (1963) defined the client as a combination of their characteristics that they use to deal with the difficulties that they have. The client is seen as vulnerable and dependent on the nurse.

A model of 'purposefully activating' acknowledges those clients who have a preference for

control over health and who have the capacity, willingness and opportunity to achieve control. Personal strengths identified in the study included client ownership of their health and a willingness to act on their own behalf. External factors included support, information and access to resources. It was apparent that external factors such as family/friends, information and inclusive health providers influenced a person's capacity and opportunity to take control over their health. It was also clear that client capacity and willingness alone may not be enough to achieve control of health. It therefore behoves health providers family and friends (where appropriate) to offer health care recipients the opportunity to be active in their health. Purposeful client activity with support, particularly from nurses, offered clients an opportunity to have a sense of control over their health care. When clients have a sense of control, they experienced feelings of empowerment which in turn lead to improved health outcomes.

The experience of illness and/or health care services may include a sense of vulnerability associated with having limited choices, a lack of information, the support of and/or family/friends and being ignored by health providers. Clients who decreased their sense of vulnerability, were more likely to achieve and maintain a sense of control if they are active, reached out to health providers (and others) and sought their support. To do this, the clients needed a sense of hope about their health situation. Findings from the study indicated that it is possible to increase a person's sense of control by supporting their activities in areas such as self-reflection, by including clients in their health care regimes, providing information that is timely and useful, offering appropriate choices and including client's relatives.

A working knowledge of the health problem is central to the activating process and decreases vulnerability. Health education can empower clients and support self-management of health (Pellino, et al. 1998). Particularly useful to

clients is information that can be revisited (Gifford, et. al 1998), personalised, self-directed (Pellino, et. al 1998), and available when needed (Kantz, et al. 1998; LaPerriere, et al. 1998).

Incorporated in this is the individual's right to accept, question and refuse treatment (Walton, 1998). Involvement is an interactive process between both the client and the health provider. Clients may or may not wish to include health providers and similarly health providers may or may not wish to include clients in their care. There is only so much that the client can do to include a reluctant health provider. Although several studies (Draper, 1997; Keatinge, 1998; Elwyn, et al. 1999; Australian Nursing Federation & Royal College of Nursing Australia 2001) have been conducted about health providers' willingness to work in partnership with clients, further work is required to explore strategies that health providers can use to involve clients in their care.

The outcome of purposively activating is that clients attempt to normalize and resume previously held roles. Part of normalising is a sense of usefulness in contributing to others and being accepted by others as normal. This may include renegotiation with self about expectations of normality and acceptance of a different level of normalising or renormalizing (Thorne 1993). Normalising comprises control of self and self-control. During normalising individuals either meet their own goals or the goals of others such as health providers or family. When individuals achieve their own goals, they have a greater sense of control; a control of self. Control of self is consistent with an internal locus of control where the individual may choose to change their own goals to suit the situation or change the situation to suit their own goals. When individuals achieve goals set by others they normalise to a lesser degree and their experience is one of self-control. Self-control incorporates fitting in with either the social or professional expectations of others. Self-control is consistent with achieving the goals of others

and an external locus of control. Individuals who achieve their own goals have a greater sense of control of the situation. Those whose actions are fruitless, who cannot meet their goals or the goals of others they may passively or actively withdraw and accept whatever treatment is offered. Alternatively, they may return to a previous phase to look for alternatives or to re-think their position and maybe re-cast their goals.

In summary, this paper has reported on research into how health care clients achieve and maintain control over their health care. It has proposed a model of purposively activating which takes clients from feeling vulnerable through to feeling back in control. Purposively activating involves the client in reflecting, being self-determiningly involved and finally normalizing.

It would not be appropriate to make broad generalisations from this study, however the findings are seen to be transferable to similar contexts. The findings from the study are useful to both clients and health providers. It identified ways through the health care system for clients who want to have a sense of control over their health care, and for health providers who want to support client control over health care. Importantly it recognises the client as an active agent in their own care and underscores the need for health professionals to support client control through providing informed choices and adequate health information; involving clients in decisions that affect them and assisting them to set and achieve goals that allow them to again feel useful and 'normal'.

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