On-line Supplement

Additional details of sample, procedure and data analysis

Methodology: The current study used a qualitative approach, following Caelli's generic principles (1). Based on the ethnographic tradition of social investigation, we sought to examine the experiences, thoughts, perceptions, beliefs and meanings of key mental health stakeholders about communicating a diagnosis of schizophrenia, and to make sense of these views through critical analysis of the data.

Sample: The participants were clinicians employed at public mental health services in an Australian regional city. Sixteen mental health professionals (7 female, 9 male) included five psychiatric registrars, five consultant psychiatrists, four senior nurses, one psychologist and one social worker. The participants had a range of experience in mental health (2–30 years) and worked in varied capacities and settings (inpatient, community, supported recovery, rural).

Procedure: Purposive sampling was used to select participants from a range of professional backgrounds and settings. All psychiatrists and psychiatric registrars were sent an invitation to participate via email. Other clinicians were selected from a variety of mental health services and sent an email invitation. Prospective participants were asked to contact the research team. Appointments were made with each clinician at a time and place convenient to them.

Semi-structured interviews were used to explore the experiences and perceptions of mental health clinicians about their communication with patients with schizophrenia and their carers concerning the diagnosis of schizophrenia. Information sought included the circumstances in which this took place, how they discussed prognosis, and their recommendations for improvement in the communication process. Interviews were conducted by an experienced Research Assistant (RA), trained in qualitative research, between September 2010 and December 2011. Interviews lasted approximately 90 minutes and were recorded and transcribed verbatim.

Ethics approval for the project was obtained from Human Research Ethics Committees. Written consent was obtained from all participants prior to entry into the study

Data Analysis: Data analysis was ongoing during data collection. Transcripts were read by Authors 1 and 2, a coding scheme agreed on. Data was coded, sorted and organized using QSR International's NVivo 9 qualitative data analysis software (2). Broad, meaningful categories and themes were developed, and relationships between themes relevant to the project were identified (3). Summaries were prepared for each theme to facilitate discussion and analysis at regular team meetings.

Additional supporting statements from clinicians

Clinicians talked about whether they recommended giving a diagnosis of schizophrenia or not and the reasons behind their decisions. A selection of additional verbatim quotes from the participating clinicians, illustrating the key themes reported in the results section of the paper, is shown below.

Yes, patients should be told they have schizophrenia

> "I don't remember a situation where I've been wanting to avoid that name. I mean, I'm aware of the situation where people are afraid the diagnosis will be schizophrenia, because they've got a family member with schizophrenia. But they usually know anyway, so beating around the bush isn't usually going to help them." (Psychiatrist)

> "... it kind of clears the air and if they do need to go and do some more research, because nowadays you've got to be clear you know, you've got to understand there's so many avenues of information, the Internet, so on an so forth." (Registrar)

Patients should be told they have schizophrenia, but it depends

Diagnostic uncertainty

> "…when they come the first time and you say "This is a first episode of psychosis," and then when they come [again] within six months we say "This is a schizophreniform disorder." Then it's only after that time that we say, "Yes, this is schizophrenia." So that's the first thing, to clarify what we mean by schizophrenia, and for people to be clear about that; maybe that's for us to clarify in our minds, it would help us to communicate that better… sometimes I'm a bit hesitant to ... say "Yes, you've got schizophrenia," because I'll be thinking, "What if it's drugs? What if it isn't a schizophreniform [disorder], have we really had enough time?" and things like that." (Registrar)

Acuteness of patient's illness and capacity to understand

> "Well, I think it depends a lot on the patient because some are cognitively able to discuss that, and some really aren't at that stage and will never really get there." (Registrar)

In contrast to another psychiatrist who stated:

> "In terms of … the acuteness of their psychosis … I don't see any problem with telling people early exactly what you think and what you think is happening. Now, there will be some people that will have limited capacity to take information in, they may be frightened, they may feel unsafe with you, they may be paranoid, they may be agitated or aggressive, which is often just because they're frightened. I still think that if you can tell people, and with people that are paranoid, the best is to be upfront with them, exactly, early on, and you don't beat around the bush. Acknowledge stress "I know you're in hospital and you're terrified, you're terrified that somebody here is going to come and kill you, but this is what I believe is what's going on, and this is what we're going to do." And I think the sooner you tell people the better, the worst thing you can do is waltz in, ask them some questions and waltz out, I'd hope nobody does that sort of thing." (Psychiatrist)

Uncertainty about patient's reaction

> "… I think it's more the anxiety about um, how the person is going to accept it and take it, and what their conception is of it, because you know the stigma and the, yeah, it's more the

anxiety about how that person's going to receive the information, how they're going to feel afterwards. I guess suicide risk is probably, would be my worst [fear]."(Senior Nurse)

"I think I, I've used those euphemisms when I've had a very psychotic patient who is aggressive, and who gets angry when I use schizophrenia." (Registrar)

Uncertainty about the effectiveness and efficacy of treatment

"I mean I have to be honest and say …from what we know, people do tend to deteriorate over time, and … they'll get well and they'll get ill, but overall they won't get quite as well …we expect it to go downhill overall. And probably explain the other things that we do know, is they're more like to have co-morbidities, like heart disease and things, partly because of their lifestyle, partly because of our medication, they will, we know people with schizophrenia have a much shorter life expectancy." (Registrar)

No, its not beneficial to the patient to give a diagnosis

Some clinicians did not, generally, advocate naming a diagnosis of schizophrenia. Clinicians who worked with younger people felt this most acutely.

"…if you've got a sixteen year old who just happens to have, you know, a severe form of the illness and has been either in hospital, or hospitalised a number of times, or has been seeing the community doctor and has been given a diagnosis of schizophrenia at that young age, I think often it can be detrimental to tell them that early on, if they don't need to know. It can be better to say, "you've had psychosis, or that we're looking at, you know, it could become, you know, that's something that could happen down the track," rather than putting that label on them." (Psychologist)

"I don't use it [schizophrenia]. If the client brings it up I'll use it, but I don't initiate it. Just because sometimes, like we'll have the paperwork that says they've got a diagnosis of schizophrenia, but they haven't actually been told. So if I brought it up, it might be quite detrimental to their kind of process of getting their head around it." (Social worker)

Additional Reading

1. Caelli K, Ray L, Mill J: 'Clear as mud': Toward greater clarity in generic qualitative research. International Journal of Qualitative Methods 2, 2003
2. NVivo 9 qualitative data analysis software; QSR International, inventor Nvivo qualitative data analysis software; QSR International Pty Ltd. Version 9, 2010.
3. Corbin JM, Strauss AC. Basics of qualitative research techniques and procedures for developing grounded theory. London: Sage; 1998