International Journal of Mental Health Nursing (2013) 22, 76-84

# FEATURE ARTICLE 'That was helpful . . . no one has talked to me about that before': Research participation as a therapeutic activity

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**ABSTRACT:** There is considerable interest in the various ethical problems associated with undertaking health and social science research. Participants in such research are often considered vulnerable because of their health status, social position, or dependence on others for health and welfare services. Researchers and ethics committees pay scrupulous attention to the identification and amelioration of risks to participants. Rarely are the benefits to participants of engaging in research highlighted or drawn to the attention of potential participants. Such potential benefits need to be considered by researchers and reviewers when considering the balance of benefits and harms associated with research projects. In this paper, we particularly consider the psychotherapeutic benefits of participation in research.

**KEY WORDS:** benefit, distress, ethics, research participation, risk, therapeutic.

### INTRODUCTION

In recent years, research methodologies, sometimes broadly construed as 'qualitative', have gained in popularity and credibility in the health and social care field. This has paralleled a growing interest (often mandated by health policy) in eliciting the viewpoints of service users, and paying greater attention to their experience of health, well-being, and recovery in the design, management, and delivery of services. Qualitative and inductive methodologies serve to give voice to the experience of service users, and these have come to be accepted as legitimate forms of

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research. Some have described qualitative methods as 'coming of age' (Taylor 2006, p. 457). Yet many research governance processes (including institutional review and human ethics committees, peer review, and editorial processes) continue to be orientated towards traditional forms of empirical research, and in particular, clinical trials, which are concerned with questions of causation, have much clearer intended consequences or outcomes, and tend to position the researcher and participants in different relationships to other forms of social research (Ramcharan & Cutcliffe 2001). One consequence of this orientation is that the potential benefits of research participation are downplayed, often go unreported in research reports, and are seldom considered in riskbenefit analyses. In this paper, we seek to address this imbalance and consider research as a potentially therapeutic activity.

Few people would dispute that the outcomes of research can be therapeutic. Although the full impact of much qualitative research can be difficult to anticipate,

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Denzin and Lincoln (2005, p. xvi) have asserted that qualitative research is a 'moral, allegorical, and therapeutic project' serving the purpose of helping people to 'endure and prevail in the opening years of the 21st century'. The process of research, as well as the outcomes, might be therapeutic. For researchers who might align with a social constructionist position in which language is understood to be both performative and constructive (Burr 2003), this is self-evident. Through dialogue with the researcher, a reality is constructed, reconstructed, or co-constructed. However, it is our contention that the process of research participation can be therapeutic in many ways, regardless of the ontological assumptions of the researcher. Such potential benefits need to be anticipated and considered (as well as potential harms) in determining the merits of a research project. Maximizing the therapeutic benefits of research participation is an important element of well-designed research, and at least in part satisfies the duty of care owed to participants by clinician researchers.

Good research governance is predicated upon the careful identification and mitigation of risks to the research participant. Typically potential harm, discomfort, or inconvenience of involvement is spelled out to potential participants from the outset. Even if some benefits of participation are anticipated, these are usually overshadowed by the caveat that 'participation might bring no personal benefit' on information sheets and consent forms. Research is considered ethically acceptable only if potential benefits outweigh the carefullyassessed risks (NHMRC 2007). The potential benefits of the knowledge to be generated by research are often highly speculative, but tend to count more in the riskbenefit analysis than the benefits of direct participation. However, the benefits of participation in research for individual participants are downplayed, but are frequently more tangible, and are revealed more quickly during the research process.

The benefits of research participation are often overshadowed by a preoccupation with risks associated with working with 'vulnerable' people. Paradoxically, it is often a focus on protecting participants from harm and cushioning vulnerable people that violates important ethical principles of autonomy and justice, whereby people might be withdrawn from research studies, not included, or their viewpoints rendered irrelevant (Rogers 2004). There are strong arguments to allow competent individuals to participant in research which poses risks (Edwards *et al.* 2004), and there have been consistent challenges to the assumptions underpinning paternalistic decisions in relation to research participation (Appelbaum *et al.* 1999; Koivisto *et al.* 2001; Stanley *et al.* 1981; Tee & Lathlean 2004). Competent individuals ought to be able to choose to participate after weighing potential benefits and harms, and it is beholden on the researcher to express these in comprehensible terms.

It is possible that participants in a study might become aware of unresolved or painful issues. Indeed, research might explicitly draw attention to painful experiences. However, the evidence that talking of one's experiences will produce uncomfortable emotions or exacerbate distress is equivocal (Munhall 2001). It is more often the case that participants experience positive emotional experiences and outcomes as a result of participation (Jorm *et al*. 2007). Where people sometimes do experience distressing emotions when reliving negative experiences, they are often transitory in nature, not necessarily undesired or overwhelming, and seen as understandable, rather than harmful (Draucker et al. 2009). By being able to talk about their experiences and connecting with others who might have had similar experiences, there is the potential for direct personal and therapeutic benefit. This is an outcome congruent with qualitative research (Duncombe & Jessop 2002; Kitzinger 1994), and often an expected outcome of participatory inquiry (Koch & Kralik 2006).

This paper had its origins in a series of conversations between the authors (all nurses), in which it was discovered that all shared experiences of having to rigorously defend research protocols submitted to review committees, and having gone to extraordinary lengths to guarantee after care or referral if participants became distressed. All could also recall that the safety net was rarely (if ever) needed, and that many participants commented on how participation had been helpful, or that people appeared to derive psychotherapeutic benefits, sometimes beyond those obtained from psychotherapeutic services. The distress that the participants sometimes experienced was largely able to be contained within the researcherparticipant relationship in much the same way that good nursing is emotionally containing.

Such reported (although 'anecdotal') evidence for benefits in participation is not confined to qualitative research. One author had undertaken a survey of people who had experienced hearing voices using a range of validated scales. It was memorable that all participants commented in some positive way; that completing a questionnaire drew attention to and encouraged discussion of experiences which had not previously been discussed and the opportunity was valued. On another occasion, in an exploration of how social care workers dealt with the deaths of service users, the researcher was somewhat surprised by how frequently people commented that talking about the experience was helpful, and indeed several participants commented that the experience of participation was a lot like therapy. Some acknowledged that they shared thoughts and feelings in conversations with the researcher that they had not shared with managers, supervisors, or personal therapists to date.

Such anecdotally-recorded benefits of research participation are rarely reported formally, as they are construed as artefacts of the research process and not the primary aims. The benefits of research participation are generally not reported, reported in attenuated form, or occasionally it is acknowledged that no harm befell participants. Russell (1999, p. 415), in a rare dissection of a qualitative study that did not quite live up to the expressed aims of exploring vulnerable older people's sense of isolation, found that people 'made intimate disclosures, enjoyed the experience, and/or derived other benefits from it'. In a recent systematic review exploring the prevalence of participant distress in psychiatric research, Jorm et al. (2007) suggested that there was no evidence of long-term harm from research participation, and indeed positive responses, such as finding some advantage in participation, feeling better, gaining insight, or self-understanding, were much more common and showed little association with distress.

### 'HELPER-THERAPY' PRINCIPLE OF RESEARCH PARTICIPATION

The desire to assist others is a powerful motivator to participate in research. In an exploratory study of why injecting drug users choose to participate in research (Fry & Dwyer 2001), over half of the respondents suggested that others (either individuals or groups) would be the main beneficiaries of their participation. Their reasons for participation were often altruistic, an expression of citizenship or of activism (e.g. to further the 'cause' of drug users as a distinct, misunderstood, and marginalized social group). The therapeutic potential of altruistic acts has long been recognized. Yalom (1995) identified altruism as being one of the 12 therapeutic factors associated with participation in therapeutic groups. In the context of group therapy, Yalom (1995, p. 79) also suggested that the core of the therapeutic process is an 'affectively charged, self-reflective interpersonal interaction', a description that could accurately describe many encounters between researcher and participant(s).

Not all research (qualitative or otherwise) is imbued with the possibility of catharsis and intense emotional experience. However, even in the field of clinical trials, in which the potential benefits of a new drug or material incentives are identified as motivators to participate, psychosocial benefits are frequently anticipated or valued by participants. Kaminsky *et al.* (2003) undertook an analysis of narrative data from 63 people diagnosed with schizophrenia, and explored the factors affecting people's receptiveness to participation in research. Seventy-nine percent of people who had participated in research previously suggested that psychosocial benefits, such as helping others, having the opportunity to interact with others or to 'tell their side of the story', increasing selfawareness, and maintaining or developing hope, were benefits that would motivate their participation.

Arguably, engaging with others in anticipation of personal benefits is not altruism in the truest sense. Nevertheless, acting with the intent to help others appears to be beneficial or therapeutic, regardless of what other benefits might accrue. Schwartz et al. (2003) found that being involved in acts intended to help was more beneficial to people's mental health than being the recipient of help. There is considerable empirical evidence for the 'helpertherapy' principle, that is, people who act with the intention of helping benefit in therapeutic ways, sometimes regardless of whether the act itself actually helped another (Riessman 1965). For example, people who work on the 12th step of the Alcoholics Anonymous programme (helping others), lead a meeting, or sponsor others are more likely to remain sober (Zemore et al. 2004).

In an examination of helping transactions in the mental health support group, GROW, giving help to others was the greatest predictor of improvements in psychosocial adjustment over time (Roberts et al. 1999). The study found that total help received was not associated with adjustment, but help that assisted in providing cognitive reframing was associated with better adjustment. Others have hypothesized that helping others in this context leads to a form of identity transformation, whereby people come to see themselves as valuable members of the community, are less preoccupied with themselves (Finn et al. 2007), and possibly sharing advice or stories helps people to positively reframe their experiences. Participation in research, almost independent of the methodology chosen, can bring benefits to participants through their altruistic intent to help others, but also through the possibility of telling stories.

# STORYTELLING IN RESEARCH AS A THERAPEUTIC ACTIVITY

Participating in social science research of all kinds typically involves telling and retelling details about an aspect of one's life to a researcher (and often to others in a group). This process is also at the heart of all schools of psychotherapy. Generally, qualitative methods seek to embrace and explore the complexities of human experience by recognizing how the individual separately constructs multiple realities (Denzin & Lincoln 2005). More recently, the use of narrative inquiry has gained popularity. The telling of the personal story gives voice to people who often find or consider themselves in a position of powerlessness (Holloway & Freshwater 2007; Sandelowski 1994), and it is considered central to the process of how human experience can be made meaningful.

There is a narrative core to the practice of human scientific research, and for vulnerable people, this can be explored through the research process (Holloway & Freshwater 2007). Narrative as a research method epitomizes the importance of storytelling, the main function of which is located in its therapeutic value of simply telling the story and being listened to by another human being (Warne & McAndrew, 2010), but it is not just about the verbalized story. The telling of the story is imbued with intersubjectivity, both conscious and unconscious, requiring the researcher to not only give attention to the individual's story, but also to the emotional subtext inherent in their narrative, and the part the researcher plays in the unfolding story.

The implicit epistemology of qualitative research should recognize the intersubjectivity as being one that affords the participant opportunity to make sense of, and give meaning to, experience (Kvale 1996). This sense making has the potential to enrich the lives of the participants through its educational, therapeutic, and/or empowering attributes (Dyregrov *et al.* 2011).

### MAKING SENSE AND SENSITIVITY AS THERAPEUTIC FACTORS INHERENT IN RESEARCH

Often qualitative research deals with or explores human emotionality and painful experiences. People have been found to benefit from involvement through having the opportunity to share feelings, gain new insights into their experiences, and to believe that their endeavours will ultimately help others (Cook & Bosley 2001; Dyregrov *et al.* 2000; McAndrew 2008). Dyregrov (2004), in a study of bereaved parents' experience of being a research participant, found that all the bereft parents experienced their participation as 'positive' or 'very positive', with none regretting their participation. People spoke of the importance of being able to help others, but they also found solace in the process of making a meaningful reconstruction when telling the story, and being more aware of their own grief process. Inherent in reconstruction is the potential for what Gregory Bateson called 'double description'. Double description, or coming to see or experience something differently, has been described as the 'pivotal and defining concept of psychotherapy' (Gibney 2003, p. 59). We assert that good research can also provide the opportunities for such new insights and experiences. Holloway and Freshwater (2007) suggest that storytelling in the research context can be a means of coping, one that might not be accessible through other avenues.

In qualitative research, there is often a clear intent to provide a mechanism for the 'voice' of marginalized and/or vulnerable groups to be heard, and through this hearing healing is expected to be facilitated. One example is the purposeful use of focus group methods to elicit stories from people who might not otherwise have the forum or opportunity to be heard (Krueger 1994; Morgan 1996). Madriz (2000) reported on the empowering nature of focus groups, where the voices and experiences of marginalized women can be recorded. Focus groups arguably offer a place for sensitive topics to be explored within a safe place and process (Kitzinger 1994; Wilkinson 1998), much like a therapeutic milieu.

The very intent of participatory research is to transform both the person and the social system. Participatory approaches unashamedly engage participants in a process intended to bring about human flourishing (Reason & Bradbury 2008). Key outcomes from methodologies and methods within the participatory worldview include emancipation, empowerment, systemic transformation, and therapeutic outcomes (Koch & Kralik 2006; Reason & Bradbury 2008). Crucial to these approaches are the facilitation of communicative spaces, where participants feel safe and empowered through genuine participatory dialogical processes (Mac Gabhann *et al.* 2010).

The area of practitioner research can prove particularly difficult to provide contextually-relevant research findings that can improve the therapeutic milieu for practitioners and recipients of care. Participatory approaches provide a useful lens to engage in meaningful practitioner research with therapeutic outcomes. For example, 'practical inquiry' (Cronen 2001) provides a pragmatic process for practitioners and service users to inquire into practice together, and through the process, bring about therapeutic outcomes for persons and the system itself (Mac Gabhann & Stevenson 2007). These approaches frequently generate new or a greater depth of knowledge, but this is through an epiphenomenon of growth and transformation of individuals.

For some participants, being able to freely express their story will be a frightening experience, and will inevitably set in motion defensive processes (Warne & McAndrew, 2010). The process of narration involves an emotional labour on the part of both storyteller and researcher. In order to counterbalance the potential for this engagement being experienced as threatening, the researcher needs to create a safe place in which emotions can be safely discharged. This is paramount, not only for the well-being of the participant, but also for the integrity of the research. It is entirely reasonable to anticipate that telling a story about a painful experience might be difficult or painful. The issue that arises is not so much who else to refer a distressed person to, should they be distressed, but rather the capacity of the researcher to create an emotionally-containing space (Bowlby 1969) is of utmost importance. For some, if not most people for whom otherwise untalked about material is shared and emotions re-experienced, this can be a corrective emotional experience in which emotional situations which could not or were not handled in the past are re-experienced and more properly worked through (Alexander & French 1946).

In order to provide a containing environment, the researcher will be required to use self, for example personability, maturity, perceptiveness, and openmindedness, throughout the interview process (Gadd 2004). In addition, the researcher will need to draw on their own personal and professional experiences, demonstrate a capacity for empathic identification, be aware of their emotional experiences of the moment, and have a sense of the current dynamics taking place in the encounter. Central to achieving this is the capacity to stay with the participant and the ability to pick out the latent content of the person's story, while at the same time implicitly accepting the patient's story (Adler & Bachant 1995). While narrative cannot elicit 'truth', as in keeping with a positivist epistemology, storytelling remains closer to actual life events, as stories anchor the person's account to concrete events with regard to both place and time, giving 'realness' to the narration (Bauer 1996).

In qualitative research such realness will be the product of the co-existence of researcher and participant, together forming the research encounter that provides a platform for making sense of experience. Winnicott (1965) suggested that we cannot help but construct the real, even when we think that we are doing no more than hearing the other's perception of it. In this situation, what is real is less important than the experience of 'realness' or the sense of something being real (Coburn 2001), and it is the 'real relationship' or personal connectedness encompassing both genuineness and realism that takes centre stage within the interpersonal encounter between researcher and participant (Greenson 1967). While genuineness requires authenticity in the here and now, realism involves the acceptance of the perceptions and experiences of the other in a way that is beneficial (Gelso 2002). Sense making is contingent on both the acceptance of other and our subjectivity as a human being and as a researcher.

As in the therapeutic encounter, researchers can demonstrate acceptance through the way in which they present to their participants. Indeed over 60 years ago, Menaker (1942), referring to the analyst, suggested that by presenting oneself as a human being being unafraid to show personality and demonstrating a friendly interest in the patient, this could liberate the patient. The patient being able to relate to an image of the analyst that more closely represents the analyst's personality, rather than one that places him or her in an all knowing position, will better facilitate a personal connection. It is suggested that this is particularly pertinent at the beginning of therapy when both individuals are getting to know each other Likewise in the research encounter, where a different temporal space to that of therapy is occupied, personal connection is vital and has particular significance for vulnerable participants, such as those who might be suicidal (Lakeman & FitzGerald 2008).

## REALIZING THE POTENTIAL OF RESEARCH AS A SAFE HAVEN

Just as research that is poorly designed might be considered unethical, the benefits of research participation might go unrealized or indeed might be harmful without the researcher exercising sufficient skill. The dynamic interaction between researcher and participant can precipitate the researcher's own lived experience becoming part of the research process. However, if such lived experiences are not differentiated, and more so, personal values and beliefs not challenged, understanding within the research relationship might become obscured. A consequence of this might be that the participant becomes defensive in terms of their narrative, only telling what they consider to be 'an appropriate story' for the researcher. This would not only be countertherapeutic, but also undermine the integrity of research findings.

As noted earlier, for the researcher, it is important to acknowledge that you go to the research encounter escorted by your own personal agenda, both conscious and unconscious, and come away with your own subjective interpretations and representations. Accepting this situation, and in particular when there is the emergence of emotional catharsis, remaining detached becomes impossible (Dickson-Swift *et al.* 2009). In terms of self as researcher, one very important and practical way of doing this is by using reflexive analysis. Reflexivity has played an important part in the evolution of qualitative research, allowing the researcher the opportunity to reflect on how knowledge and understanding have been developed within the context of their own perspectives of the research encounter. The reflexive process enables the researcher to explore his/her impact on the interpersonal dynamic of the research encounter through ongoing selfcritique and self-appraisal (Finlay & Gough 2003).

The processes that can be used for self-critique, selfappraisal, and ultimately, self-care, include clinical supervision and the keeping of a reflexive diary (Dickson-Swift et al. 2009). Clinical supervision facilitates understanding of what is happening within the patient-therapist or participant-researcher encounter, where there is a reciprocal influencing of one human being with another. While the unconscious cannot be empirically observed, its effects can be explored through the way in which re-enactments of emotions and attitudes that belonged to important early relationships can manifest in the immediate encounter. Again, parallels can be drawn between the therapeutic encounter and the research encounter, as any research setting is imbued with both conscious and unconscious processes and meaning. The part played by the unconscious in the construction of our own reality, which in turn determines our perception of others, cannot be underestimated (Clarke 1999). This is significant both in the generation of research data and construction of the research environment. The process of clinical supervision allows the researcher to explore such re-enactments with a person external to the therapeutic/research encounter, enabling the exploration of what has taken place during each interaction with their participants, how their emotional response might have impacted on that encounter, and not least, how the participant's emotionality has impacted on the researcher. While live clinical supervision can challenge blind spots that might occur through the defended self, reflexive notes can provide a backdrop for the research, giving context to the researcher's own story of the research encounter.

#### CONCLUSIONS

In this paper, we have argued that research participation involves processes that are frequently therapeutic in nature or often benefit participants. There is growing evidence that a range of qualitative methodologies have therapeutic potential. The telling of personal stories as part of the research process can in itself be a therapeutic activity, as participants are offered the opportunity to make sense of their experience.

As qualitative methodologically-informed research studies become more common in health and social care, researchers and research review committees quite rightly pay scrupulous attention to the identification and amelioration of risk to those who might become involved in research projects. However, the potential benefits of participation ought to be drawn to the attention of potential participants; for example, that talking about a problem can be helpful. The potential benefits of being involved in research need to be considered by researchers and reviewers when considering the balance of benefits and harms associated with research projects. Indeed, it might even be reasonable to expect that research involvement does lead to particular social and psychological benefits, although these sometimes cannot be specified in detail apriori.

While there is no certainty that every person will benefit from research participation, generally there are tangible moral, if not psychotherapeutic benefits, relating to the exercise of choice to participate, and the sense that one is contributing to the well-being of others or the collective good. The intent to help others is thought to contribute to the effectiveness of participation in self-help groups, and it is likely that this is also true for activities, such as research participation. In research involving participants' telling their stories or exploring experience, the benefits might be greater still, including the psychologically-important processes of feeling heard and consolidating memories. Exploring an experience or aspect of an experience in depth, as is often the case in qualitative research, is rarely undertaken outside of therapy, and much the same processes can be at play in the researcher-participant relationship. Of course, research is not therapy, and this acknowledgement between parties might even contribute to the creation of an interpersonal space free from the demands and expectations associated with therapy, and paradoxically make for even more of a potent therapeutic activity. While this proposition is speculative, and ought to be explored in empirical research, it can account for why participants have so often reported to these authors that participation has been helpful.

Research participation can be potentially harmful, although the risks involved with exploring even distressing experiences in depth have not been clearly established, and indeed on balance, the evidence appears that such exploration tends to be beneficial for most. This does not objurgate the responsibilities of researchers and governance bodies to ensure that a safety net is available should people require it. However, the central concern should be a focus on what is needed to ensure that the research space is indeed a 'safe haven', a therapeutic space. Does the researcher have the requisite skill set, qualities, and support system to contain strong emotions should they arise, and thus enable people to tell their story? The Australian National Statement on Ethical Conduct in Human Research (NHMRC 2007) states that researchers should have enough experience or access to expertise to enable them to engage with participants in ways that accord them due respect and protection. A measure of this respect is that those who undertake qualitative research on sensitive topics or with vulnerable populations have some training in psychotherapy and/or are supervised by those that do.

The authors of this paper are all psychiatric/mental health nurses by background, and all have had explicit training in one or more schools of psychotherapy. Arguably, this background, while no guarantee of virtuous practice, at least suggests a capacity to be with distressed people, and facilitates a safe, if not therapeutic, environment. Much like the social role of mental health nursing, the therapeutic benefits of research participation are often rendered invisible. Warren and Allan (1997, p. 37), in this journal, emphasized 'getting through' ethics committees, and the important role of nurses/clinicians in ensuring that respondents are 'well enough' to participate in research. As more nurses now engage in research, we propose it is timely to promote and begin to formally account for the therapeutic benefits of research participation.

A researcher is not a mere witness to a person's story, rather they are implicated in the person's story from the moment a person consents to participate. Thus, they have a duty to assist the experience of research participation to be positively integrated into the participant's life narrative. This is a challenge for educators, supervisors, and researchers, which ought to be made explicit in associated processes. That many people are likely to find participation personally helpful ought to be acknowledged on information sheets and in conversations with researchers. Further research ought to address how to make it more so.

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