

ORIGINAL ARTICLE

Sharing the agenda: pondering the politics and practices of occupational therapy research

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Abstract

Aims: Occupational therapists espouse a client-centred philosophy of practice, yet little attention has been given to pondering the politics or client-centred practices of occupational therapy research. The aim of this paper is thus to foster reflection on occupational therapy's commitment to client-centredness in the practice of occupational therapy research. **Major findings:** Occupational therapy research is not consistently undertaken in a collaborative manner. Power resides in control of the research agenda and participants' priorities can be supplanted by those of researchers. However, examples from the literature and from the authors' research suggest that study participants may wish to influence the research agenda such that their needs and priorities are addressed. **Practice conclusion:** Client-centred principles appear to require occupational therapists to undertake collaborative research and to ensure that research agendas are informed by clients' priorities. Commitment to client-centred principles demands concerted efforts to identify and address potential barriers to meaningful client participation in the occupation of research. However, it is argued that if researchers and disabled people collaborate, and pool their knowledge and expertise, they may achieve research that is more philosophically compatible with espoused professional values; and that collaborative research may also inform more relevant and useful client-centred clinical practices.

Key words: *client-centred practice, focus groups, participatory action research, post-colonial theory*

Introduction

Although occupational therapists have been challenged to acknowledge the political nature of their work (1,2), little attention has yet been given to either the politics or practices of occupational therapy research (3–5). Research practices have been critiqued, however, by critical disability theorists, who have stated that: “in the way it has been conceived, organised and conducted, as well as in the nature and use of results, traditional disability research in ... rehabilitation ... has been

carried out by representatives of professional groups with little or no consultation with, or involvement of, disabled people themselves (other than as research subjects)” [(6), p. 152]. Clearly, this appraisal sits uncomfortably with the collaborative, client-centred philosophy that is said to underpin occupational therapy's practices (7), and merits consideration of the degree to which occupational therapy researchers engage in collaborative research with disabled people.

The term *disabled people*, used throughout this paper, is employed by critical disability theorists to

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signify that people who have impairments are disabled by social and political responses to their differences (8). Of importance to occupational therapists, and to the subject matter of this paper, is the understanding that to “disable” is to “deprive of power” (9). Thus, people with impairments – who may have considerable abilities – do not “have” disabilities, although they may be disabled (3). Importantly, if people who have impairments are deprived of power, they may be disabled by the research process.

Client-centred practice is an approach to practice fundamentally concerned with realigning power and with ensuring that occupational therapy is informed by, and relevant to, clients’ lives, values, and priorities (7,10). Research is one of occupational therapy’s practices, yet there has been little discussion about how client-centred philosophy influences occupational therapy research such that research is informed by, and relevant to, clients’ lives, values, and priorities. Client-centred practice is usually discussed in terms of clinical practice, although no rationale has been offered to justify the exclusion of research practice from this overarching philosophy. On the contrary, it has been argued that occupational therapy’s espoused commitment to client-centred practice ought to include the practice of research (4) and, further, that collaborative – or participatory – research is conceptually compatible with both client-centred practice and with occupation-based practice (11).

Disability theorists contend that research undertaken collaboratively by consumers and researchers increases both the relevance of research and its impact (12,13), and may help to bridge the gulf – or theory/practice gap – between the worlds of academe and of clinical practice (14). Moreover, it has been suggested that if researchers and disabled people pool their expertise, there is the potential to achieve better research (15).

Because legislation in several countries now requires health and social service providers to ensure that clients have direct input into the evaluation of services, collaborative research is becoming both an ethical and a legal requirement in these jurisdictions (3,16). In the United Kingdom, for example, occupational therapy researchers are expected to work collaboratively and to involve consumers at all stages of the research process (17). In North America, some funding agencies invite disabled people to collaborate in identifying issues that require research, and actively involve them in reviewing grant applications to ensure the relevance of research and the potential value of anticipated outcomes (18).

Pollard et al. (2) observe: “There is a growing awareness in occupational therapy of the need to address the political contexts in which practice,

education and research take place” (p. xvii). The current political context in which occupational therapy research takes place is one of increasing demands for meaningful consumer participation (3,16). However, in 2000, Townsend et al. (19) observed that few occupational therapy researchers were involved in collaborative research. In an effort to appraise the degree to which occupational therapy researchers have engaged in collaborative research with disabled people, a comprehensive review of the occupational therapy peer-reviewed journals (1999–2009) was undertaken using the CINAHL database. Only 18 articles (out of 4290) were found to describe collaborative research undertaken by occupational therapists with clients or consumer groups (unpublished data). This would seem to suggest that occupational therapy’s client-centred rhetoric is not reflected in the profession’s research practices. Because occupational therapy practices are said to be framed within a collaborative, client-centred philosophy (7) the purpose of this paper is to foster reflection on the collaborative, client-centred practices of occupational therapy research and to encourage occupational therapists to enable meaningful client participation in the occupation of research.

Whose research agenda?

Occupational therapists have discussed client-centred practice for over two decades and have defined this as practice that emanates from the client’s perspective (7). Because research is one of occupational therapists’ practices, there would seem to be an obvious answer to the question: Whose perspectives should inform the agenda for occupational therapy research? However, disabled people claim that research agendas are usually determined not by those who are the espoused beneficiaries of research, but by academics, clinicians, and funding bodies (20). This is an expression of power, for as McKnight [(21), p. 31] observed: “there is no greater power than the right to define the question”. Although the imperative for occupational therapy to be evidence-based continues to energize the profession’s interest in research, critics contend that much of the rehabilitation evidence-base itself is flawed because it has been developed from research undertaken without consideration of the issues that matter to disabled people (22,23). Moreover, Macfarlane (16) claims that collaborative research with service users “highlights the distortion – rather than the neutrality – of research conducted from a supposedly objective distance” (p. 203).

It has been claimed that those people who know what it is like to live with a specific condition “will have a good idea of which research questions are worth asking, and when a research question should

be framed differently” [(24), p. 724]. It is difficult for researchers to know whether their questions are worth asking, or which questions are worth asking, if they do not ask. However, evidence suggests that study participants often strive to provide this sort of valuable information, by “writing in the margins”.

Attempting to influence the agenda: writing in the margins

Many researchers who have used quantitative surveys have noted the tendency for respondents to write comments in the margins of their questionnaires in apparent attempts to describe the context for their responses and to provide relevant information about important questions the researchers failed to ask (25,26). This may suggest that those who are the subjects of research desire more input into the research process than they are often permitted, and that they may be attempting to influence the research agenda such that it addresses their priorities and needs and those issues they perceive to be important, so that research is more client-centred.

For example, Clayton et al. (25) employed a quantitative survey to enable the refinement of a model to guide the development of health-related interventions for people with multiple sclerosis. Acknowledging that questionnaires have inherent limits, because they only obtain answers to those questions the researchers deem worth asking, the researchers discovered that fully one-quarter of their respondents had added comments to the margins of the questionnaire, often despite considerable writing difficulties. Primarily, the respondents wished to describe the context for their answers to the standardized questions and to explain important and relevant issues about which the researchers had failed to enquire: “You didn’t ask but I thought I would tell you” (p. 516).

In another study, Warms et al. (26) used a quantitative survey to gain insight into the experience of living with chronic pain for people with spinal cord injury or amputation. Over half their respondents wrote comments on the survey forms, which sometimes extended for several pages. “Respondents critiqued the research questions, the methods of gathering data, and the focus of the research in general” (p. 250), with several stating, “This is what you should be asking...” (p. 249). Drawing from their experience of living with pain and impairment, many respondents outlined what “needs to be known” (p. 250). Advice included “critiques of what was being asked, how it was asked, and ways to obtain better results”, while some participants “expressed concern that the questionnaire did not ask what was important to them” (p. 250). Indeed, some felt the survey

questions revealed a lamentable lack of knowledge on the part of the researchers. These critiques are important, because by challenging the relevance of the research questions these disabled people contested the value of the research findings. However, because researchers often employ assistants to process their quantitative findings, they may be unaware of the valuable qualitative data that has been written to them in their margins.

In an effort to foreground the perspectives of some of the participants in our own studies, the following section highlights instances in which they have endeavoured to insert their perspectives and assert their agendas. Two contrasting methodologies are presented to illustrate different approaches to research and to enacting our profession’s espoused client-centred principles.

Example 1. Dictating the agenda: researcher-centred research

A quantitative study was undertaken (by KRWH) to explore the relationship between perceived levels of social support and levels of anxiety and depression among people with either severe traumatic brain injury (TBI) or spinal cord injury (SCI), and their partners. The research, which was planned in a traditional colonial manner – without any input from people with either TBI or SCI – used two standardized interviews to capture data that could be converted to a quantitative score and analysed statistically. [Study details published previously (27,28)]. However, it was apparent that the participants’ spontaneous comments provided data that were more instructive than their responses to the standardized questions, and the researcher jotted these comments in the margins of the questionnaires.

In response to the study’s questions concerning daily social interactions, a man who had been a successful architect before he sustained a severe TBI stated: “Your questions are making me feel like a reject from society”. This not only confirmed that research is neither a neutral activity nor one without consequences for those whom we choose to study, but also suggested that without input from disabled people, issues may be approached in ways that may be offensive or irrelevant. The research did not expose the reasons why his social interactions were so limited because these types of questions were not part of the standardized script, and it was therefore impossible to determine how his restricted life could have been enhanced. Indeed, by maintaining a firm grasp on power, the researcher significantly restricted and pre-scripted the parameters of knowledge that could be learned from the study participants.

In response to a question concerning community living, the wife of a man who had sustained an SCI blurted out: “They thought at the Spinal Centre that the important thing was to be able to transfer. He still can’t – but it doesn’t matter. He’s happy and I’m happy. There are more important things.” This was a profound statement, but one that remained unexplored because the research agenda was not focused on issues of importance to the research participants but on issues pre-determined by the researcher. Clearly, this participant was trying to convey something she felt was important and a pertinent dimension of knowledge was lost because the researcher did not explore the things that might make life happy after a severe traumatic injury, but stuck, instead, to the standardized script. Regrettably, despite occupational therapy’s espoused allegiance to practising in a client-centred manner, this example of research practice remains unexceptional, even in the twenty-first century.

It is important to note that the nagging concerns about power, which arose during this study, were not necessarily the consequence of using quantitative research methods. Qualitative methods do not inevitably ensure equality, but can reinforce the status quo of power just as effectively as quantitative methods (29). Power dynamics cannot change unless researchers work conscientiously to change them.

Example 2. Sharing the agenda: collaborative research

People with SCI (18,30) and researchers (31) have identified fatigue as an issue of priority for research. In an attempt to enhance the relevance and usefulness of research by working in partnership with people living with SCI (3,18,32,33–35), and in an effort to enact occupational therapy’s client-centred principles (7), a study into the experience of fatigue following SCI was planned, undertaken, analysed, and reported by a collaborative research team of occupational therapy academics, and peer counsellors from the British Columbia Paraplegic Association.

Seeking a client-centred approach to data collection

The focus-group method was chosen by the team to enable participants to define their priorities, explore those issues they deemed important, assert their perspectives, and develop their analysis of a common experience (36,37). Because focus groups can enable a high level of participant involvement (37) and are a relatively non-hierarchical research method (38,39) they hold considerable promise as a client-centred research method. By virtue of the number of research participants, focus groups have the potential to shift

the balance of power towards the participants and away from the researcher, to enable participants to assert their own agendas and to develop the themes most important to them (39). Within the group context it may be easier for research participants to challenge researchers’ views or assertions and even to change the direction or focus of the research (39). Importantly, working with groups can place demands for accountability on researchers because the group dynamic cultivated within the focus group is likely to produce expectations for action (40). However, without a sincere commitment to sharing power with group participants, focus groups can be as hierarchical and researcher-driven as any other research method. (A full description of this research, including its purpose, process, outcome, and planned action, are reported elsewhere) (41,42).

Asserting and inserting agendas

Although it is possible that some people might feel constrained by a group research method and be unable to express their opinions, we found that the focus-group format fostered discussion and enabled participants to raise concerns that had not been anticipated by the research team. Several focus-group participants spontaneously expressed frustration with previous research in which they had been involved, which they felt lacked both relevance and a commitment to action. For example, they were frustrated with medical research that had enquired whether the pain they experienced was burning or tingling yet had failed to ask about the impact of pain on their lives. Moreover, after participating in previous research they had not received any feedback concerning the research findings or the actions planned by the researchers to address these findings. This prompted participants in one focus group to question what research accomplishes, and for whom. They complained:

“It gets frustrating . . . it is just all these studies”; “Studies study, but what have you learned?”; “It is tiring”; “It is not only tiring, it is a waste of money”; “Did anything come of it?”

Focus group leader: “So, . . . much more research needs to be grounded in the self-expressed needs of the community?”

“And actually followed through on”; “So that it has some use”.

There was a clear expectation on the part of these participants that researchers are responsible for ensuring that research yields meaningful results and actions, an expectation compatible with client-centred practices.

Congruent with the suggestion that focus groups can enable participants to assert perspectives that may

differ from those of researchers (39), the participants in one group insisted that fatigue was a symptom of a more profound problem, and challenged the researchers on the underlying premise of the research itself:

“It’s okay to talk about fatigue, but that word – throw that word aside. Really, it’s like you’re getting bent on a word. . . . A major part of why you go through what you go through is because you feel hopeless, feel tired”;

“I think it’s a symptom of something bigger than what we’re talking about here. . . . I’m going to throw your whole thing out of the water. . . . I don’t think fatigue is really what we’re looking at”;

“I don’t either. I agree”.

The participants’ insights informed subsequent efforts to develop and appraise appropriate interventions to address the relationships they identified between fatigue, pain, depression, and a sense of helplessness or hopelessness, thereby broadening and deepening the original research focus on fatigue (42). One participant also suggested an insightful direction for future research: “Maybe a research project for another time could be: If 60% of people with spinal cord injury experience this fatigue [and] 40% don’t, Why? What’s going on here?”

Power, politics, and research

Critical disability theorists have long observed that irrespective of whether researchers employ qualitative or quantitative methods, the power of the researcher is enshrined in their control over the research design, process, analysis, and dissemination of research findings (20,32). Because research participants do not always receive feedback from researchers, they may be unable to learn what conclusions have been drawn from the research or what actions will be undertaken in light of the study findings (43,44). It should not be surprising, therefore, that although some people find participation in research to be empowering and rewarding, others have reported that the research process can be disempowering and claim that the absence of tangible results provokes anger and frustration (45).

It is also important to note that research is not an entirely altruistic endeavour, but one that can yield rich rewards for researchers, enabling students to attain degrees and academics to accumulate papers and conference presentations, and achieve peer recognition, promotion, research grants, and tenure (3,46).

Critics observe that research is a political occupation, either reinforcing or countering existing power differentials (40,47). Indeed, Foucault (48) viewed knowledge and power as so inseparable that he termed this relationship power/knowledge. Therefore, to

contemplate the practice of research – the generation of knowledge – is inevitably to confront issues of power.

Power, politics, and occupational therapy research

Power is integral to the occupation of research. Identifying a research question and data collection method, analysing data, and disseminating knowledge all require choices, and these choices are informed by perspectives, values, and priorities. At all these decision points, power resides in control (49), with power either shared with participants, or monopolized by researchers. Although critical disability theorists have long claimed that “central to the problem of rehabilitation is the failure to address the issue of power” [(50), p. 104], occupational therapists have only recently begun to engage seriously with theoretical analyses of power (2,3). Moreover, occupational therapists have not subjected the politics of their research practices to significant critical analysis (4,5) despite espousing a client-centred orientation to practise fundamentally concerned with power (3,51). It is helpful, therefore, to draw from the work of postcolonial theorists, who have paid considerable attention both to power and to the occupation of research.

Critical theory and research

Postcolonial theory is a form of critical theory specifically concerned with empowerment of the dispossessed, the establishment of minorities’ rights, and with achieving just and equitable relationships among people (52,53). In particular, postcolonial theorists examine how marginalized and disempowered people (those who are considered to be “inferior” on the basis of normative judgements about physical ability and appearance, colour, behaviour, etc.) are represented, marginalized, and disempowered by those wielding more power. Thus, it has been suggested that critical post-colonial perspectives should inform disability research (3).

When a research issue is defined by the researcher, the research process is controlled by the researcher, and the findings are analysed and disseminated according to the researcher’s perspectives and priorities, this reflects a colonial methodology (54). Post-colonial theorists claim that researchers must develop an awareness not only of “who speaks, from where, and for whom” [(55), p. 89], but also of whose perspectives are discounted, suppressed, or unacknowledged. These are political choices. However, they do not occur in a vacuum, but in a political context (2), with client-centred aspirations challenged by the competing demands of funding

agencies, institutional stakeholders, and career aspirations (3).

Enabling meaningful participation in research

Evidence-based practice and client-centred practice are claimed to be the two most influential paradigms in current health-care practice (56). To reflect their client-centred philosophy and to ensure the relevance and usefulness of research evidence, occupational therapists need to identify effective means of including consumers in research to ensure it addresses the values and priorities of those whom research has traditionally been “about”. As a first step, for example, some researchers have sought to identify the research priorities of people with specific diagnoses in an effort to develop a research agenda addressing issues of importance to clients (e.g. 33). This enables research to achieve a client-centred focus, even if the research process itself is not collaborative. Expanding this process to ascertain the research priorities of clinicians might also be a means to address occupational therapy’s current theory/practice gap.

How might the practice of occupational therapy research better reflect the client-centred, collaborative ethos claimed to underpin the occupational therapy profession (7)? As in all client-centred practices, client-centred research builds on the premise that everyone’s contributions have equal value (57) and is characterized by meaningful and reciprocal partnerships in all phases of the research process, a non-hierarchical approach to power, mutual respect for the equally valuable yet different knowledge, skills, and perspectives contributed by all team members, an openness to learning by all parties (by being unthreatened and constantly challenged by ideas and perspectives contributed by other team members and research participants), and a commitment to translate research results into meaningful action (14,33,58,59). Greenwood and Levin (58) note that community research partners “contribute urgency and focus to the [research] process, because it centers on problems they are anxious to solve” (p. 96). Thus, collaboration with those people traditionally used solely as research “subjects” demands a high standard of accountability.

Collaborative research presents unique challenges, due to the politics of organizations (policies, procedures, and practices) and the politics of professionalism (60), the time-consuming nature of research, and the need to achieve a balance of expertise and sufficient funding to ensure participants are compensated equitably. Although considerable debate within the occupational therapy profession has focused on institutional barriers to client-centred clinical practice, little attention has centred on

either the institutional or professional barriers to client-centred research practice. However, issues involved in overcoming barriers to collaborative research are now beginning to be discussed in the occupational therapy literature [e.g. 11,61], and exemplars of client-centred occupational therapy research are increasingly to be found in the literature [e.g. 62,63].

Recent research demonstrates that disabled people’s organizations want to be engaged actively in shaping research agendas (12) and to be involved as partners in designing, implementing, disseminating, and evaluating research of relevance to their priorities and needs (13). Moreover, disabled people are identifying those factors that they perceive as constituting barriers to their participation in research with academics (13). If the occupational therapy profession is seriously committed to collaborative, client-centred practices, concerted attention could usefully focus on how barriers to client participation in the occupation of research might be identified, addressed, and overcome.

Conclusion

Evidence demonstrates that occupational therapy research practices do not consistently reflect the client-centred ethos said to underpin the profession. Moreover, little attention has been paid to the politics of occupational therapy research, or to the institutional and professional environments in which research is undertaken. Examples in this paper suggest that research participants wish to influence agendas to make research more relevant to their needs and priorities.

Power dynamics cannot change unless researchers work conscientiously to change them. By enabling clients to share in establishing research agendas, and by engaging in collaborative research, occupational therapists are more likely to develop evidence-based theories and interventions that are informed by, and relevant to, clients’ lives, values, and priorities.

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