

Core elements of programmatic research in nursing: a case study

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In this invited paper Tina Koch and Debbie Kralik present the establishment of a research program outside the precincts of a university and we ask Gary Rolfe to provide a commentary from the perspective of an academic. We argue that a dedicated research unit, with a clearly articulated philosophy and in response to research questions from clients, community and practitioners, provides the focus to drive the program. Although we have infrastructure from the RDNS Foundation, obtaining external funding to support our program is a central activity. Discernable outcomes of our collaborative inquiries are described as participants with whom we research narrate aspects of their experience, leading to enhancement of self agency and quality of life. We illustrate the reform potential as groups of research participants develop sustainable people networks. Most importantly, theoretical development is ongoing describing transition (ways in which people are able to take a chronic illness into their lives and move on) and better understanding on ways in which health care professionals can facilitate transition. Evidence based news letters are written in collaboration with practitioners, however we ponder about ways to further our research findings in practice. Gary Rolfe speculates about intermural or extramural research programs. He frames his response using Brand's criteria to research program decisions. In order of importance he asks: (1) will it be fun? (2) will we learn anything from it? (3) will it make the world a better place? (4) will it earn enough money to pay for the first three? Gary argues that one of the luxuries of working within the university sector as an academic is that he can occasionally ignore question four.

Key words: programmatic research, collaborative research, nursing research, chronic illness

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Introduction

What is a research program? What are the core elements of programmatic research? Are research programs important for nursing? This paper seeks to answer these questions by discussing the steps taken in the development of a long-term nursing research program. The steps discussed here reflect a dynamic approach to a collaborative research program that is regularly revised and refocused on the basis of lessons learned through our research actions and outputs, successes and failures. Most importantly, our research endeavours are guided by the collaborative partnerships with health workers and the community that constitute the centerpiece of this research program.

This paper was written collaboratively by the three authors who corresponded by email between Adelaide and Swansea in the United Kingdom. Tina Koch is Director of the RDNS Research Unit in Adelaide however during the time of writing this paper, was visiting professor at the University of Wales (Swansea). Gary Rolfe is Professor of Nursing at the University of Wales, and Debbie Kralik is Senior Research Fellow in the RDNS Research Unit. This paper reflects the deliberations that have occurred between the authors, and as such we felt it important to convey the richness inherent in our different perspectives and experiences. To achieve this, Koch and Kralik describe the development of a chronic illness experience research program developed in a community setting, and Rolfe follows with a commentary and insight about development of a nursing research program from an academic perspective.

Underpinning philosophy

Tina Koch and Debbie Kralik are researchers and nurses working in the community, hence we have embraced primary health care (PHC) principles to guide our research and nursing practice. The key aspect of PHC philosophy has been researching *with* people; hence we have been guided by the principles of participatory action research (PAR). Guided by the work of Stringer (1999) PAR principles enable a potentially democratic process that is equitable and liberating as participants' construct meaning during facilitated, group discussions. The cyclical nature of the PAR process promotes reflection and reconstruction of experiences that can lead to the enhancement of people's lives, either at an individual and community level or both.

Our research program has been in progress since 1996 and has been shaped by a collaborative research approach and guided by participatory action research (PAR) and PHC principles. Since Lewin's seminal work in the 1940s, action research has emerged as a critique of traditional approaches in social science (Reason and Bradbury 2001). Rather than making causal links between predictor and dependent variables based on data from past events, this research approach has aimed to understand past events and to explore ongoing dynamics of human interactions in the present and further prepare for future intentions through joint organising with all stakeholders.

Each inquiry starts with everyday experiences of people living with chronic illness and their development of living knowledge. As people narrate their stories they start to hear their life anew through hearing and prompts made by the others (Koch 1999, Aranda 2001, Brody 2003, Frank 1995, Holstein & Gubrium 2000). The narrative process creates the possibility to 'reconstitute and repair ruptures between body, self and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams 1984 p197). When possible, participants are co-researchers, and we collaboratively decide on action and what can be done to 'make' or shape the future.

Articulation of a research program

Our chronic illness experience research program has focused on how people learn to live with long term illness and incorporate the symptoms and consequences of illness into their lives. We have researched *with* both men and women who have diverse chronic conditions. Our chronic illness experience research program has been consolidated by collaboratively researching with more than 200 men and women living in the community with adult-onset chronic illness (Koch & Kralik 2001, Koch, Selim & Kralik 2001, Kralik, Koch, Price & Howard 2004). Recruitment of participants has crossed diverse medical diagnoses and relied upon the participant's own construct of living with symptoms of chronic illness (Kralik 2000, Kralik Koch & Webb 2001). We have researched with people who have multiple and complex diagnoses including multiple sclerosis, fibro myalgia, asthma, arthritis, schizophrenia, HIV and diabetes. Findings have revealed that psychosocial consequences such as changes to employment, relationships, reshaping of identity, and symptoms such as pain and fatigue are shared across medical category groups. When we have researched with people who have a specific medical diagnosis it has been because this has been the focus of the funding body (MS Australia, Diabetes Australia). We will share the emerging constructs based on theorising and experience from a broad range of projects and across chronic illness experiences.

Emerging Constructs

Our research program has been informed by people's storied accounts of experiences with a diverse range of chronic illness and conditions. A major construct of transition in illness has emerged which people experienced as convoluted movement between states of Extraordinariness and Ordinariness (Kralik

2000, Kralik 2002). Extraordinariness was manifested when people were first confronted by the changes to their sense of well-being that are imposed by an illness or condition; they experience turmoil and difficulty in coming to terms with the intrusion of illness. They may experience an assault to the taken-for-grantedness of their everyday lives, in addition to dealing with the impact of physical manifestations of illness. Profound disruption, isolation, powerlessness and loss accompany the impact of chronic illness. One participant described her world as "laying like shattered glass" at her feet when illness intruded. Illness becomes a focal point and there may be a perceived lack of control over the seemingly constant disruption to every facet of their lives as completing common daily routines becomes difficult. Physical changes and sensations may exacerbate a feeling of being betrayed by their bodies.

Most people have experienced a powerful sense of loss exacerbated by the inability to continue work in paid employment, changes to sexual feelings which may result in modification to sexual practices, shifts in relationships, the inability to parent effectively, loss of spontaneity in life, and loss of control over both their lives and bodies. Self-absorption may dominate their perspective on life; however, our research has revealed that the process of focusing on, thinking through and turning over these thoughts, feelings and responses may provide the impetus for the passage to Ordinariness.

People experience Ordinariness when they have learnt ways to manage and incorporate the constant change imposed by chronic illness into their daily life. We have found that people who are in supportive relationships may experience a smoother transition toward Ordinariness because acknowledgment by others assists in the reconstruction of self-identity (Koch, Kralik and Eastwood 2002). Through reflection on their experiences and responses to illness they develop an altered perception of self that has enabled them to reclaim control. Illness becomes a part of life. Actively making choices to reshape their lives provides an important sense of progress. Feelings of being betrayed by their body are replaced with a desire to nurture it. People in Ordinariness develop a sense of mastery over, and responsibility for their responses to illness. Through the day-to-day experience of living with illness, they learn that maintaining themselves in Ordinariness means incorporating the consequences of living with chronic illness into their lives. In these ways, a sense of order is created.

The transition between Extraordinariness and Ordinariness is a convoluted process embedded in, and impacted upon by the context of life. Our recent research has aimed to explicate this complex transition and to achieve this; each research project we undertake is a building block towards new understandings of chronic illness experience.

We are concurrently working with both men and women who live with chronic illness in the effort to describe transition (Australian Research Council Discovery Grant 2003-2005) guided by the principles of PAR bring people together in email discussion groups. A web site provides more detailed information about the background to that research

http://www.unisa.edu.au/nur/arc_project/ . Seventy percent of RDNS clients live with a chronic illness and so the relevance of this research is clear. Meanwhile our chronic illness program has gained international standing, multi-disciplinary acknowledgment and has been granted further competitive funding from ARC and NHMRC. The main theoretical trust of this program has been understanding the way in which people make transitions. Each project builds incrementally upon our understandings.

Outside the field of chronic illness experience we have applied our theoretical understanding of transition in a capacity building program with homeless women who have been sexually abused during childhood. Story telling and reclaiming self identity is part of that work (Gergen 1971, Kleinman 1998, Kelly & Field 1996, Nettleton & Watson 1998, Brody 2003). Further, a book to be published by Penguin in March 2005 explores transition with 24 centenarians (authors Tina Koch, Charmaine Power and Debbie Kralik). We were interested to hear stories of transition throughout the lifespan so we travelled across Australia to interview these dynamic older people.

Implications for practice

Transition is about a passage of change (Kralik, 2002) and our aim is to understand this process better so that we, as health care professionals, can facilitate our clients and community moving forward in sickness and health promotion. We concur with Meleis and Trangenstein (1994) and Schumacher and Meleis (1994) that fundamental to nursing is the facilitation of clients, families and communities through transition. Our tentative understanding of transition is that people can and do move on, and that these shifts are accompanied by changes in self identity and self agency. We have become strong advocates of 'narrative nursing' and participatory action as facilitators of transition. Listening to the storied accounts of peoples' lives gives coherence and meaning to both parties. In life story work people are able to reconstruct their identity conjointly with the researchers (and practitioners). However, in practice, these peoples' storied accounts live outside formal care plans. Taking time and being interested in the storied lives of those for whom we care shows we are building collaborative relationships, which in turn may lead to partnerships with our clients and community through the health care system and life. Transition, we contend, is central to nursing practice.

Engaging community nursing clinicians has been fundamental to our chronic illness research program. The research question is often identified in nursing practice. Clinician involvement is evidenced by clinicians as co-authors on papers, and presenting research findings at conferences. Where possible, we facilitate clinician involvement at every aspect of the research process, however organisational and workload constraints have been obstructions. Research findings are also disseminated throughout the organisation and tertiary institutions in a newsletter which is published monthly and posted on the Internet (www.rdns.net.au).

What are core elements?

We have articulated a research program underpinned by primary health care principles emphasising social justice, equity and health promotion in our research *with* clients and community. A strong commitment to making a genuine contribution to nursing and community health care, which is validated by participants, is the driving force behind our research activity. Whilst this may not be a core element for research programs in general, it drives our efforts. Methodological strength is easily identified in our endeavours through publications. In other words topic and methodological strength coincide.

Of course research is not possible unless there is funding. We believe we have been successful with external funding agencies because the research question often emerges from the practice of community nurses and health workers. We are responsive to the needs of the community and in our community, 70 per cent of RDNS clients have chronic illness. Responsiveness, relevance and reform in health practice are believed to be core elements to our research program.

It was fortunate that several years after we had commenced our chronic illness experience research program, the federal and state governments turned their attention to chronic disease self management (CDSM) and we found ourselves embroiled in policy debates about ways to proceed with research. Government prioritised funding in areas of chronic illness and as we had a publishing track record in the area of chronic illness we were well positioned to apply for these funds. It is important to keep abreast of national research priorities, and large funding bodies publish priority areas for funding. One example is the large amounts of funding made available for AIDS/HIV research during the early 1990s; however this funding has since reduced considerably. Predicting where governments are going to spend could become a preoccupation and realising that funding for specific health areas will eventually dry up needs to be recognised as a political reality.

Building theoretical understanding (and/or knowledge) of transition is a core element of our research program. Building understanding or knowledge we contend is an important element for all research programs. Evidence that 'building' has occurred can be demonstrated by the number and focus of publications. We commenced with small grants, sometimes only \$5000, but we planned publications regardless. There have always been interesting findings to be reported. During the past eight years we have published more than 60 papers, chapters or books as a direct result of our research endeavours.

Writing for publication is a disciplined, but pleasurable daily activity, and developing a track record of publications has assisted in making our research proposals attractive to funding bodies. Important also is the consideration of the journal where our research manuscripts have been placed. We have endeavoured to publish in international journals that have easy access through the large search engines such as Ovid and CINAHL. This strategy has assisted in the wide dissemination of our research findings and often been the impetus for national and international partnerships.

Being focused is an essential core element. Once a research focus is identified, plans can be made for subsequent research proposals and strategically where funding may be sought. We plan proposals for funding more than one year ahead of time so that our program can be sustained. We recognised early in our research careers that proposal generation efficiency and skill was a core element, not to be delegated to novice research assistants. Rather we choose to collaboratively generate our own proposals.

Building a research team is equally important. Although the authors have worked together for many years, we have attracted likeminded researchers, often people who have completed their PhD and have sought to further their research training through post doctoral studies with us. In addition, four PhD candidates are currently working on the transition thesis in their areas of interest. Mentoring and learning from others has been an important element within our research unit. We have identified a process of a 'learning circle' that occurs when guided by participatory principles in our research relationships. A focused, critical research community is an obvious enhancement to our research program and an element of importance. Our critical community incorporates both researchers, clinicians and past research participants who have maintained an interest in our research program.

National and international acknowledgement is often the outcome of prolific publication. Koch and Kralik have both been invited to advance the research program and share the emerging transition findings internationally. Connecting with researchers from chronic illness research programs elsewhere has been extremely fortuitous with cross fertilisation of ideas and wider international collaboration being some of the outcomes. Again this enhances external funding possibilities and enables the program's sustainability.

One other key element has been the utilisation of research findings in practice. We have recently convened a panel of senior clinicians within our organisation where the aim is to develop processes that facilitated the transition of research findings into practice. This has developed into another way to engage clinicians with the research process. When we have completed the ARC (Discovery) project describing transition we anticipate we will be able to articulate the theoretical content and this process for uptake by other health care practitioners. The way in which our research findings are utilised remains the single most problematic aspect of our research program. How does one stimulate enough interest for significant findings to be incorporated into every day health care practice? It is our hope that this paper raises the interest of nurse researchers, administrators, educators and clinicians throughout Australia for serious debate and consideration of inclusion of the transition thesis in everyday health care practice.

What are the constraints?

It is well known that dedicated research units are more productive than environments where academics teach research and somehow manage a myriad of other activities. The RDNS

Research Unit is situated outside the university and infrastructure. Support is provided by the RDNS Foundation (the fund raising and charitable arm of the service). This financial support has secured our strong presence in a competitive university environment. We have produced a research environment that has attracted expert researchers and PhD candidates. In 2004, the RDNS Research team consists of eight researchers.

As an autonomous research unit we are able to work with colleagues across Australia and in the United Kingdom. We have status and links with the three universities in Adelaide, the University of Western Sydney, and Universities across the United Kingdom. We suggest that collaborative endeavours may be more successful outside the competitive confines of universities.

One of the constraints has been the lack of dedicated nursing research units in universities. We argue that a concerted effort is required to plan, implement and sustain a research program. It is naive to expect that programs can be built without a dedicated focus. Academics and practitioners simply do not have the time to pursue research activity including writing for publication. Teaching in the morning and researching in the afternoon fragments the effort. Many of our university colleagues view teaching as central and it is working alongside their students that gives them satisfaction. Often research activity (external grants and publications) are a requirement for promotion or tenure. It seems clear that some people thrive on teaching whilst others are researchers, very few can be both.

In terms of grant success, academics are more likely to find themselves chasing funding not necessarily in a strong area of interest or in response to questions from practice. Fragmentation of interest and focus are deterrents for building a research program. Generating and building 'new' knowledge may be similarly constrained when obtaining grant funding involves a frenzied chase on seemingly unrelated topics. Our advice to nurse researchers is to develop a planned program of research, which incorporates a focused topic area and theoretical framework as opposed to 'dabbling'.

Rolfe's commentary: some speculation

This commentary presents a viewpoint that is in many ways similar to that described above, but in other ways quite different. My own programme of research shares a very similar philosophy and methodological approach, subscribing fully to the values and methods of participatory action research. There are, however, notable differences. Firstly, my work is mainly with service providers rather than service users. Secondly, I am employed by a public sector university and my remit includes teaching and other teaching-related administration. Thirdly, and perhaps most significantly, my programme of research is far smaller, produces far less output and, by whichever measure you chose to apply, is less successful than the RDNS Research Unit. This of course, means that I am less able to draw on my experiences of what makes a successful programme of research; what I have to offer is less retrospective experiential knowledge of what actually works, and more like idle speculation of how things might be different.

Three or four core elements for a research programme

I came across the work of management consultant and Renaissance man Stewart Brand in the mid 1990s and have since tried to apply his criteria to my research program decisions. Briefly, he argued that the questions we should ask ourselves when planning a work program of any kind are, in order of importance (Eno 1996):

1. will it be fun?
2. will we learn anything from it?
3. will it make the world a better place?
4. will it earn enough money to pay for the first three?

One of the luxuries of working within the university sector is that, unlike Tina and Debbie, I can occasionally ignore question four.

I will now explore and examine some of the issues raised earlier in relation to Stewart Brand's four questions.

Will it be fun?

This is the first and perhaps most important question of all, but one which is rarely addressed in research circles. It is certainly the first question I ask myself in relation to new projects, since if the answer is 'no', there is little point in asking the others. When Freud was asked what were the two most important elements of a fulfilled life, he reportedly answered: 'sex and work'. It is clear from his writing (eg Freud 1930) that work offered an important source of satisfaction and enjoyment (and fun!) and that job satisfaction is closely associated with life satisfaction. Furthermore, there are established links between fun and creativity (Koestler 1964), such that having fun might be good not only for the individuals involved, but also for the success of the project.

Will we learn anything from it?

For the researcher operating from within a university setting, this has traditionally been the key question. The aim of research (indeed, the very definition of research) has traditionally been the discovery or generation (depending on whether you are a realist or a constructivist) of knowledge. This view of the aim of research is to some extent reflected in the research program described by Tina and Debbie, and clearly there is much to be learned from the 'storied narratives' that they produce, not least by the story-tellers themselves. As Tina and Debbie note, 'as people narrate their stories they start to hear their life anew...' Narrative is a long established way of constructing and presenting knowledge, and one which some have argued should be placed on a par with scientific knowledge (Lyotard 1984).

Tina and Debbie however, are also attentive to the difficulties of research-as-knowledge-generation, particularly within a practice-based discipline such as nursing. Thus, they point out that the utilisation of research findings in practice is the single most problematic aspect of their research program. Some researchers might argue that this should not, in fact, be their concern, but is rather a problem for the consumers of the research. Indeed, a number of studies over the years (see Seymour et al 2003 for a summary) have argued that the reasons for research not being translated into practice are that nurses do not read research reports, that they do not

understand research reports and that they do not or cannot implement the findings of research reports.

There are at least two responses to the problem of the translation of knowledge into practice. Firstly, the problem is to some extent alleviated by research units being situated in university settings. Although Tina and Debbie point out the problem that 'teaching in the morning and researching in the afternoon fragments the effort', we might reframe the issue such that researching in the morning and teaching in the afternoon is actually a single unified act of knowledge generation and dissemination. This was certainly the argument put forward by the early pioneers of educational action research in the UK and Australia (for example, Carr & Kemmis 1986, Elliott & Ebbutt 1985), for whom research questions arose naturally from their practice of teaching and the findings of their enquiries were seamlessly integrated back into their everyday work as teachers.

Secondly, Tina and Debbie have already gone some way to implementing the findings of their research *directly* and without the intervention of practitioners. PAR cannot help but bring about change; the very act of participating in a PAR study has therapeutic benefits for the participants. As pointed out previously, 'when possible, participants are co-researchers, *and we collaboratively decide on action and what can be done to "make" or shape the future.*' Thus, the role of the practitioner is to some extent circumvented by the therapeutic effects of participation in the study. However, a more powerful model might be to work directly with service providers in the same way that they work with service users. By facilitating practitioners to generate their own research questions, to research their own practice, and to implement and evaluate the findings of their research in an action research cycle, the problem of implementation is largely overcome.

Will it make the world a better place?

If the question of learning from research can be addressed by bringing together the roles of researcher and lecturer, then the question of making a difference can be addressed by merging those of researcher and practitioner. Tina and Debbie are insistent at the outset that 'we are researchers and nurses' (not researchers who used to be nurses), and appear to acknowledge the therapeutic aspect of research when they write that their research program is 'underpinned by primary healthcare principles' and that 'having a strong commitment to make a difference in healthcare drives our research.' As Kurt Lewin, one of the founders of action research wrote: 'Research that produces nothing but books will not suffice.' (Lewin 1948 p202-3). In practice disciplines such as nursing, this might almost be turned into a moral imperative, such that research for its own sake or research purely as a means of generating income simply will not do. We could argue that nursing research has to 'make a difference' or it is not worth doing. Of course, all healthcare researchers might argue that they aim to make a difference, but as we have seen, action researchers aim to make a direct impact on healthcare rather than merely hoping that practitioners will read and implement their findings.

In my own research programme, the roles of researcher and practitioner are combined through facilitating practitioners to research their own practice. Tina and Debbie, as we have seen, approach the problem from the opposite direction, suggesting that *research itself* has a therapeutic benefit if it is conducted in a certain way by certain people with certain attitudes towards themselves, their role in the process, and the research participants. This notion of the researcher-practitioner is well established in other healthcare disciplines. The work of Freud, for example, might be seen as the archetypal example of the idea that facilitating the 'patient' to tell her/his story constitutes a therapeutic activity. Indeed, it is sometimes difficult to tell whether Freud is writing up therapeutic case notes or reporting on case-study research (Freud 1977).

Of course, researcher-practitioners can only make a difference if they are asking the right research questions and addressing the most pressing needs. Tina and Debbie are particularly successful at this, although I suspect that they are being rather modest when they put 'being in the right place at the right time' largely down to luck. As action researchers working alongside health service users, they are constantly in touch with the issues of concern for patients. Furthermore, if (and this is perhaps a big 'if') government policy eventually responds to service users' needs, then it is hardly surprising that they will be constantly anticipating forthcoming calls for research bids in a way that traditional researchers could only dream of doing.

Will it earn enough money to pay for the first three?

Which, of course, brings us to the question of funding. For Stewart Brand (and for me) this is the least important of the core elements of programmatic research, but for many researchers it is vital to the continuation of their program. As Tina and Debbie point out, the unfocussed academic 'is more likely to find herself chasing funding not necessarily in a strong area of interest or in response to questions from practice.' Certainly, the 'publish or perish' culture in most universities has resulted, as Tina and Debbie observe, in 'grant funding being chased regardless of topic', and it is for this reason that, although funding is the lifeblood of many research units, it is placed at the bottom of the list of questions for the researcher to ask herself with regard to new projects. Only once we are sure that the project is fun and worthwhile do we ask ourselves whether it will be self-financing. However, we have seen that if the researchers are constantly in touch with the needs of service providers and users, then this question will not even arise, since the issues that we and our practitioner and service user partners consider to be worthwhile will be the very same issues that the funding bodies are offering to finance.

Conclusion

We have presented a case study of a research program that resides outside the walls of the university and asked an academic to make some observations. We have drawn on our experiences to identify the core elements of programmatic research and some of these are debated. We agree however that the objective of programmatic research in nursing is to

systematically build upon an area of knowledge (methodological and/or topical) by:

- Development of nursing or multi disciplinary research teams which can make a greater impact and be competitive nationally and internationally.
- Providing a group of researchers working in common areas of interest, with a platform for exchange of ideas and expertise.
- Providing the academic and research milieu whereby young researchers, including graduate students and clinicians can access comprehensive research training and mentoring.
- Maximising the sharing of research experiences, skills, equipment and other resources required for research.

We also agree that research is an enjoyable, passionate endeavour, the results of which we hope will make a difference in the wider community and continue to advance nursing.

References

- Aranda S 2001 From individual to groups: use of narratives in a participatory research process. *Journal of Advanced Nursing* 33(6):791-797
- Brody H 2003 *Stories of sickness* Oxford University Press, Oxford
- Carr W & Kemmis S 1986 *Becoming critical: education, knowledge and action research*. Falmer, Lewes
- Chick N & Meleis A 1986 Transitions: a nursing concern. In: Chinn P (ed) *Nursing Research Methodology*. Aspen, New York, pp237-257
- Elliott J & Ebbutt D 1985 *Issues in teaching for understanding*. Longmans, Harlow
- Eno B 1996 *A year with swollen appendices*. Faber & Faber, London
- Frank A 1995 *The wounded storyteller*. University of Chicago Press, Chicago
- Freud S 1930 *Civilization and its discontents*. Cape & Smith, New York
- Freud S 1977 *Case Histories 1: 'Dora' and 'Little Hans'*. Penguin, Harmondsworth
- Gergen K 1971 *The saturated self: dilemmas of identity in contemporary life*. Basic Books, New York
- Holstein JA & Gubrium JF 2000 *The self we live by: narrative identity in a postmodern world*. Oxford Books, New York
- Kelly M & Field D 1996 Medical sociology, chronic illness and the body. *Sociology of Health and Illness* 18(2):241-257
- Kleinman A 1988 *The illness narratives. Suffering, healing and the human condition*. Basic Books, New York
- Koch T 1999 Story telling: Is it really research? *Journal of Advanced Nursing* 28(6):1182-1190
- Koch T & Kralik D 2001 Chronic illness: reflections on a community based action research programme. *Journal of Advanced Nursing* 36(1):23-31
- Koch T, Selim P & Kralik D 2001 Enhancing lives through the development of a community based participatory action research programme. *Journal of Clinical Nursing* 11:109-117
- Koestler A 1964 *The act of creation*. Hutchinson, London
- Kralik D 2000 *The quest for Ordinariness: midlife women living through chronic illness*. Unpublished PhD thesis, Flinders University of South Australia, Adelaide
- Kralik D 2002 The quest for Ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* 39(2):146-154
- Kralik D, Koch T & Webb C 2001 The domination of chronic illness research by biomedical interests. *Australian Journal of Holistic Nursing* 8(2):4-12
- Kralik, D, Koch T, Price K & Howard N 2004 Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing* 13(2):259-267
- Lewin K 1948 *Resolving social conflicts; selected papers on group dynamics*. Gertrude W. Lewin (ed). Harper & Row, New York
- Lyotard JF 1984 *The postmodern condition*. Manchester University Press, Manchester
- Meleis A & Trangenstein P 1994 Facilitating transitions: redefinition of the nursing mission. *Nursing Outlook* 42:255-259
- Nettleton S & Watson J 1998 The body in everyday life: an introduction. In: Nettleton S & Watson J (eds) *The body in everyday life*. Aspen, New York, pp1-24
- Reason P & Bradbury H (eds) 2001 *Handbook of action research*. Sage, London
- Schumacher K & Meleis A 1994 Transitions: a central concept in nursing. *Image: Journal of Nursing Scholarship* 26(2):119-127
- Seymour B et al 2003 Valuing both critical and creative thinking in clinical practice. *Journal of Advanced Nursing* 42:288-296
- Stringer ET 1999 *Action research*, 2nd edn. Sage, Thousand Oaks
- Williams G 1984 The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness* 6:175-200