

Oral presentations

001 OP

UCL QUALITATIVE HEALTH RESEARCH SYMPOSIUM 2015: ENRICHING QUALITATIVE INQUIRY IN HEALTH

A Baim-Lance,^{1*} G Black,¹ H Llewellyn,² LM McGregor,³ C Vindrola-Padros,¹ M Vňuková,⁴ C Vrinten³. ¹Department of Applied Health Research, University College London, UK; ²Marie Curie Palliative Care Research Department, UCL Division of Psychiatry, University College London, UK; ³Health Behaviour Research Centre, Department of Epidemiology and Public Health, University College London, UK; ⁴Department of Epidemiology and Public Health, University College London, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.1

The field of health research appears increasingly open to qualitative approaches. We celebrate the rise in qualitative and mixed methods publications and the marked presence of qualitative researchers in academic centres of health research. However, we note enduring tensions between the conceptual and methodological approaches of qualitative research and those of a quantitative paradigm, generally more familiar to health practitioners, policymakers and often other researchers. In some instances, qualitatively-oriented investigations continue to conflict with the expectations within health research to provide concrete and timely findings and recommendations. These concerns foreground questions to be explored around the applicability, value, contribution, legitimacy and limitations of qualitative inquiry within the prevailing research culture.

In recognition of these questions, we curated a day long symposium around abstracts submitted in response to an open, internationally disseminated call, framed to create a productive space for the critical examination of the current state of qualitative health research, and the exploration of ways to enable its enrichment.

We organised the papers, posters, keynote address and panel discussion into three themes. The first, *Problematising the research landscape*, reflects on particular issues arising when we 'do' qualitative research. The second, *Re-approaching familiar frameworks*, explores the application of epistemological traditions of the social sciences to understand health, and to consider what underpins how we frame and treat such topics. The third, *Imagination at work—enriching the potential*, attends to the prospects of bringing new approaches into research, sometimes borrowed from other fields.

The symposium facilitated engagement with current research and reflections on connecting methodological advances with theoretical traditions amidst challenges of carrying out applied health research. A perceived need exists for qualitative researchers to concertededly promote and enrich our contributions without homogenising or obscuring what our approach has to offer. This could be achieved through the continued development of a common platform for qualitative research that facilitates collaborations and fosters interdisciplinary education and training. This symposium represents critical steps towards these aims, to be further developed through the convening of future events.

Problematising the research landscape

002 OP

EXPLAINING DISCREPANT RESULTS FROM QUESTIONNAIRES AND INTERVIEWS CONCERNING HELP-SEEKING: ARE 'PUBLIC' AND 'PRIVATE' ACCOUNTS THE KEY?

CM Dobson,^{1*} SR Brown,¹ AJ Russell,² GP Rubin¹. ¹School of Medicine, Pharmacy & Health, Durham University, UK; ²Department of Anthropology, Durham University, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.2

Social surveys and interviews are staple methods within health research. One of the perceived merits of the postal questionnaire is the anonymity it affords to participants, enabling people to provide honest accounts, particularly in relation to sensitive topics. Interviewing can potentially introduce bias to participants' accounts because of a compulsion to provide socially desirable responses. Here we examine these assumptions through a comparison of questionnaire and interview accounts of the help-seeking experiences of people with symptoms of cancer.

Public discourses of early diagnosis of cancer are increasingly commonplace, particularly after the 'Be Clear on Cancer' campaigns, which reinforced the importance of consulting quickly when experiencing cancer symptoms. This study aimed to explore the help-seeking experiences of people with symptoms of lung or colorectal cancer by inviting patients to complete a questionnaire about their symptom onset and first consultation with a health care practitioner. A sub sample of these participants were interviewed about their help-seeking experiences, with the interviews taking place within 8 weeks of the questionnaires being returned.

We found that the reported length of the help-seeking interval (time from first symptom to first consultation with a health care practitioner) differed in questionnaire and interview accounts for the majority of participants. Whilst we may have expected participants to report longer intervals in the questionnaire, because of its perceived ability to reduce social desirability bias, we found that the converse was true; for most of the cases where there was a discrepancy in interval length between questionnaire and interview, longer help-seeking intervals were reported in the interview.

We shall consider possible explanations for these unexpected results, suggesting that the concept of 'public accounts' and 'private accounts' provides insight into these discrepant participant responses. The formality of the questionnaire and the closed nature of questioning may encourage participants to report more socially acceptable behaviours in order to conform to public discourses around early help-seeking and early diagnosis. Whereas in interviews, participants were able to report more deviant accounts because they were within the private setting (their homes) and were able to narrate their stories and detail their reasoning.

003 OP

CHALLENGES IN QUALITATIVE INQUIRY: JUDGEMENTS OF 'ETHICS' AND 'QUALITY'

F Stevenson,^{1*} W Gibson,² C Pelletier,³ S Park,¹ V Chryskou¹. ¹Department of Primary Care and Population Health, University College London, UK; ²Department of Culture, Communication and Media, Institute of Education, UK; ³Department of Lifelong and Comparative Education, Institute of Education, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.3

Background UK-based research conducted within a healthcare setting generally requires approval from the National Research Ethics Service. Research ethics committees are required to assess a vast range of proposals, differing in both topic and methodology. We argue the methodological benchmarks with which research ethics committees are generally familiar and which form the basis of assessments of quality do not fit with the aims and objectives of many forms of qualitative enquiry and their more iterative goals of describing social processes/mechanisms and making visible the complexities of social practices.

Our research Drawing on the challenges we encountered gaining ethical approval and subsequently conducting a study of junior doctors' decision-making in an Emergency department,

we suggest there is an urgent need to re-think the ways that ethical issues are currently conceptualised. In particular, we argue that embedded in the current paradigm is a restricted notion of ‘quality’, which frames how ethics are developed and worked through. Specific, pre-defined outcome measures are generally seen as the traditional marker of quality, which means that research questions that focus on processes rather than on ‘outcomes’ may be regarded as problematic. We illustrate the importance of re-visiting the notion of ethics in healthcare research. Specifically, we consider the need for an alternative ‘iterative’ paradigm and outline how this offers a useful starting point for moving beyond these limited views.

Conclusions A ‘one size fits all’ standardisation of ethical procedures and approach to ethical review acts against the production of knowledge about healthcare and dramatically restricts what can be known about the social practices and conditions of healthcare. Our central argument is that assessment of ethical implications is important, but that the current paradigm does not facilitate an adequate understanding of the very issues it aims to invigilate.

004 OP

ENACTING PPI IN QUALITATIVE MENTAL HEALTH RESEARCH: PEER RESEARCHER INVOLVEMENT IN DATA ANALYSIS IN THE ‘CORE’ STUDY

N Morant,* B Lloyd-Evans, CORE project team led by S. Johnson. *Division of Psychiatry, University College London, UK*
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.4

Patient and public involvement (PPI) is now an expected component of UK publicly-funded health research. Compatibilities with PPI aims and values mean that qualitative research is often a vehicle for enacting PPI. This presentation focuses on the involvement of “peer researchers” (service users and carers) in qualitative data analysis, and offers critical reflections of the practicalities of this process in the context of mental health research and an academic-led project.

“CORE” (Crisis resolution team Optimisation and Relapse prevention) is a large NIHR-funded research project that aims to optimise the functioning of crisis resolution teams (CRTs). CRTs provide intensive home-based treatment for people experiencing an acute mental health crisis, as an alternative to hospital admission. They exist in all NHS Mental Health Trusts in England, but their performance and effectiveness is variable. The CORE project adopts a collaborative model of service user and carer involvement within an academic-led project. A large service user and carer working group contributes to a range of project activities including a qualitative study of stakeholders’ views on current and best CRT practice, in which peer researchers have conducted interviews and been involved in data analysis.

Faced with a large data set of more than 100 pieces of data, and little existing guidance on peer researcher involvement in qualitative data analysis, we attempted to develop an approach that enabled genuine involvement and maximised the methodological benefits of collaboration. Additional aims were to build research skills and capacity, and to obtain feedback from participants about their experiences of this. Peer researcher involvement began in the early stages of thematic analysis, in order to maximise contributions to the development of thematic codes at the point when these were most fluid and open. This was part of a staged process that meshed the work and perspectives of peer researchers with those of the academic researcher team. The

presentation will describe this process and the rationale behind it, and discuss critical issues such as whether academic-led collaborations perpetuate or have the capacity to challenge existing power inequalities that are greater in mental health than other healthcare contexts.

Re-approaching familiar frameworks

005 OP

ON THE NEED FOR PRACTICE THEORIES IN HEALTH SERVICES AND POLICY RESEARCH: LESSONS FROM QUALITATIVE INQUIRY

J Shaw. *The Institute of Health Policy, Management and Evaluation, University of Toronto, Canada*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.5

Researchers in the fields of health services and policy generally focus on optimizing the organization and practice of health care in order to ensure best possible outcomes for patients and the public. This broad mandate variably entails evaluating the feasibility of new service delivery models, devising interventions that achieve better outcomes, and studying populations to tailor specific health care initiatives and programs. Implied in these various foci of health services and policy research is a normative logic of implementation, which can be formulated something like this: If researchers find the truth, then practitioners should use it. However, the widely discussed and longstanding “gap” between evidence and practice strongly suggests that this “logic” of implementation must not be very logical at all.

In this paper I suggest that the lack of “uptake” of research findings in practice provides a gateway to elaborating on two key conceptual issues in health services and policy research. The first issue is regarding what constitutes knowledge in everyday health care practice, otherwise known as epistemologies of practice. The second issue, building on the first, is regarding how the practice of health care providers actually comes to be and thus how it can be changed. Understanding the knowledge and practice of health care providers requires an understanding of practice in its broadest theoretical sense, as the coordinated activities of everyday experience through which our ongoing lives derive their meaning.

Drawing on the findings of a comparative qualitative case study of transitions from hospital to home in London, UK and Toronto, Canada, I will illustrate how conceptual advances in theories of practice provide great insight into (a) the knowledge that health care providers create and use in their everyday practice, (b) why health care is practiced exactly the way it is, and (c) how it might be changed for the better. Demonstrating the value of insights from qualitative applications of practice theories, as demonstrated by the qualitative findings presented in this paper, I call for a shift toward the more systematic use of practice theories in health services and policy research.

006 OP

METHODOLOGICAL LIMITATIONS AND ADVANCES IN STUDYING CULTURE AND MENTAL HEALTH: SIGNIFICANCE OF QUALITATIVE APPROACHES

R Patel. *The University of Nottingham, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.6

Social Epidemiology has had a long standing position in health research and covers distribution and determinants of health-related states in defined populations. The domain investigates

patterns and causality, revealing health inequalities which aim to prevent and control health related issues. Understandably this field of research has advanced biological fields in exploring the relevance of social, cultural, environmental and economic factors that also play a fundamental role in ill health which is crucially ignored in biological standpoints. However, the dynamic of current societies is continuously changing and for example some areas in the UK are distinctively culturally diverse. By using my study of exploring reasons behind low reported rates of mental illness within the Gujarati community in Leicester I will argue that Social Epidemiology is limiting as method of studying in particular ethnic groups and mental health.

This presentation will firstly, address the current problems with epidemiological studies in this area such as ecological fallacy, cultural stereotypes and validity of official statistics. Secondly, I will argue that qualitative research and sociological approaches are progressive for studying mental health. With reference to interview data I will outline a few current cultural complexities such as religion, language and changing traditions faced by both first and second generation migrants.

Finally, I will conclude by proposing to progress mental health provision for ethnic groups there is much to be learnt about the intrinsic relationship culture has on mental health. Both qualitative methods and sociological approaches accommodate this required necessity. Having recognised the significance qualitative research has in health, we are faced with the problem of incorporating this in the universal province of the medical model of health which indeed is tricky and perhaps not one that is welcomed by all.

007 OP

THE USE OF MIXED METHODS IN ASSESSING WELLBEING BENEFITS DERIVED FROM A HERITAGE-IN-HEALTH INTERVENTION WITH HOSPITAL PATIENTS AND CARE HOME RESIDENTS

HJ Chatterjee,^{1,2*} L Thomson². ¹Department of Genetics, Evolution and Environment, Division of Biosciences, School of Life and Medical Sciences, University College London, UK; ²UCL Public and Cultural Engagement, University College London, UK

*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.7

The role of non-clinical interventions in health and social care is attracting increased interest as the value of community based assets in public health gains support. For the last six years University College London researchers have explored the advantages of a mixed methods approach to assess the therapeutic benefits of museum-focused interventions in healthcare settings including hospital wards and care homes. Using a combination of qualitative grounded theory and thematic analysis together with quantitative measures has resulted in a robust appraisal of the potential of handling and discussing museum objects in terms of positive effects on cognitive stimulation, health and wellbeing. Measures consisting of the Positive and Negative Affect Schedule (PANAS) and Visual Analogue Scales (VAS) taken before and after object handling sessions of around 40 minutes showed increases in positive emotion and decreases in negative emotion with improvements in subjective wellbeing and happiness. Qualitative analysis of audio recordings from the sessions were used to account for how improvements in wellbeing were brought about and revealed that mutual exploration of the objects led to deeper thinking and meaning making, and acted as a distraction from the clinical environment. Interview data

gathered from participants, carers, health and social care staff provided a more nuanced understanding of the impact of a non-clinical intervention and led to the development of best practice guidelines for those working in museums and health. The research, which is funded by the Arts and Humanities Research Council, has led to further funding to investigate the value of museum engagement in social prescribing. ‘Museums on Prescription’ will connect socially isolated, vulnerable and lonely older adults, referred through local NHS and Local Authority Adult Social Care services, to partner museums in Central London and Kent. A combination of qualitative and quantitative methods will be used for analysis of interview data and measures of wellbeing and social isolation taken before, during and after 10 weekly, two-hour, museum sessions, and at three and six month telephone follow-ups, to provide insights into non-clinical prescriptions and a psycho-social model of health rather than reliance upon a purely medical model.

Imagination at work—enriching the potential

008 OP

EXCURSUS ON THE IMMUNE SYSTEM: MELTING HISTORY, STORIES AND MICROBIOME DATA

A Nunez Casal. Department of Media and Communications, Goldsmiths, University of London, UK

10.1136/bmjopen-2015-UCLSymposiumAbstracts.8

The microbiome seems to challenge the tenet of a self-contained human nature by recognising the role of microbes along with ecological and lifestyle factors in the shaping of the immune function. Those features, in turn, are specially valuable and timely for critical debates in the social sciences and humanities around notions of biological identity and embodiment as well as for evaluating post-genomics with regards to a molecular-based 20th century biology.

In an attempt to map cross-roads for traffic to and from biology, geopolitics and philosophy, this paper develops a critical cartography of the immune system, to which I refer to as ‘excursus on the immune system’, by bringing together the two main elements that conform my research project:

- ▶ Empirical insights from Lady Montagu’s journeys, who in 1718 imported the variolation technique from Turkey to the UK
- ▶ Ethnographic fieldwork of Dr. Dominguez-Bello’s microbiome expedition in the Amazon (2011–2013) as part of the research ‘Microbiomes of Homes across Cultures’

I will particularly focus on how the historical analysis of Montagu’s diaries and my field notes articulate with health data resulted from microbiome research. I will also discuss how I supplement the aforementioned methods to secondary research methods, which include attending scientific conferences as both data collection and research training, informal conversations and formal interviews, discourse analysis of media reports and specialised scientific literature on the microbiome, and a digital ethnography of ‘American Gut’, a personalised microbiome project.

My preliminary results show that both the environment and microbes refigure immunity as a rather different object rendering notions of the self as bounded, universal and autonomous increasingly difficult to maintain. Moreover, the fact that the environment, not just genetics, produces differences among bodies, immunities and microbes highlights questions of (bio) inequalities as obligatory points of passage for contemporary social studies of science.

009 OP

A SOCIOGRAM IS WORTH A THOUSAND WORDS: PROPOSING A METHOD FOR THE VISUAL ANALYSIS OF NARRATIVE DATA

D Contandriopoulos,^{1,2} C Larouche^{2,3*}. ¹Université de Montréal, Faculté des sciences infirmières, Montréal, Québec, Canada; ²Institut de recherche en santé publique de l'Université de Montréal (IRSPUM), Montréal, Québec, Canada; ³Department of Anthropology, McGill University, Montréal, Québec, Canada
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.9

This presentation proposes and showcases an innovative method for the visual analysis of narrative data. This method rests on three steps: the transformation of narrative data into relational data, the use of graph optimization algorithms derived from social network analysis (SNA), and, finally, the visual analysis of the resulting sociograms. This method was developed and pilot tested in the context of a research project about stakeholders' views on the strengths and problems of Quebec's health care system, and the solutions needed to increase its performance and sustainability.

SNA is a transdisciplinary methodological approach focused on understanding the structure of the relations that connect different elements. The scope of its application is very wide, from understanding the structure of molecular interactions and disease transmission in epidemiology to the analysis of kinship structures and community organization in anthropology. Although SNA has a long tradition in social sciences, its mainstream acceptance is recent.

This presentation begins with a brief summary of the specificity, origins and evolution of SNA tools, followed by a discussion on how the reliance on relational analysis differentiates SNA from other paradigms used in qualitative and quantitative analysis. It then provides an overview of the narrative data analysis method we developed and illustrates it via a case study on different perspectives of the Quebec health care system. Lastly, we outline the originality, potential and applicability of using SNA-based methods to analyse narrative data collected in qualitative health research.

We will argue here that examining how actors and their opinions constitute a network-like structure offers promising ways of interpreting data. In our research, the use of this method presented two main advantages. It provided powerful data visualization that facilitated the inductive identification of the underlying structure of our data. It also revealed the complexities of the links between differently positioned actors in the Quebec health care system that a personal attribute-based analytic method would have overlooked.

010 OP

MAKING CHRONIC PAIN MATTER—HOW CAN QUALITATIVE RESEARCH SHAPE THE CONVERSATION?

E Gonzalez-Polledo,* F Cornish, J Tarr. *Department of Methodology, London School of Economics and Political Science, UK*
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.10

This paper reflects on our experience of designing, running and evaluating participatory qualitative research methods to better understand pain communication. It emerges from *Communicating Chronic Pain: Interdisciplinary methods for non-verbal data*, a research project funded by the National Centre for Research Methods, which aimed to bridge the gap between experiencing and communicating about pain. Focusing on non-verbal forms of communication instead of personal illness narratives, this project explored pain communication in

non-clinical contexts, analysing non-verbal forms of pain expression across multiple social media platforms and by using arts methods as experimental and participatory methodologies to explore pain communication.

Involving a mixed group of people living with different forms of chronic pain, clinicians and pain researchers, we set up a series of four workshops which were designed as a context in which participants could collectively explore dimensions of pain communication beyond individual pain narratives. Each of these workshops was collaboratively led by two arts practitioners and attended by our team of three researchers as full participants. Workshops were structured around a process of making or working with objects (drawings, photographs, soundscapes and spaces). We analysed both the content of participants' communication about pain, and the processes enabling that communication. Regarding content, the methods yielded evocative and relational versions of pain that encompassed tensions (such as immediate/chronic; owned/disowned; internal/external), rather than repeating traditional linguistic distinctions. Regarding process, we argue that the combination of practical arts methods and inclusive, anti-hierarchical social relations fostered a context which allowed for ambiguity and multiple meanings, in ways that are not traditionally enabled in the context of clinical communication.

In this paper we ask Did this type of experimental/participatory workshops succeed at reframing pain in ways that could improve clinical communication? What practices worked best in terms of participant engagement? Could this format be taken forward as a form of collaborative, open-ended, participatory research practice?

Keynote presentation

001 KP

THE CURIOUS INCIDENT OF THE QUALITATIVE RESEARCHER IN APPLIED HEALTH RESEARCH

S Shaw. *Unit for Social Policy & Practice in Health Care, Queen Mary University of London, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.11

Qualitative research is widely used as a means of understanding and analysing a range of health and care issues. Qualitative researchers are a diverse group who use interpretive approaches to make the world visible (for instance, through case study, interviewing or participant observation). This makes them well-placed to study health care and to apply findings in practice and yet few describe themselves as doing 'applied health research'. This raises the question as to whether applied qualitative health research is alive and kicking or whether, like the dog in the opening paragraph of Mark Haddon's book^a, it's lying on its side with its eyes closed and seemingly dead? In seeking to answer that question, this paper focuses on current challenges facing qualitative researchers working in applied settings.

There is a vibrant community of qualitative researchers who are doing applied health research and who aspire to make a difference to people's lives. High quality research is being undertaken that should not only make a difference but also raise the profile of qualitative health research. However, involvement in applied health research often involves compromises about the ways in which we work. It tends to involve multidisciplinary teams working together for short periods of time on specific problems in the real world, and it often requires researchers to work across disciplines and teams, proactively manage relationships, combine research methodologies and reconsider theoretical or

epistemological concerns. Those working in applied health research need to take care not to give up some of the important elements of qualitative research to the methodological hierarchy that mixed-methods designs sometimes presume in which quantitative methods are at the top and qualitative methods are relegated to a largely auxiliary role. They must ensure that methodological and disciplinary differences are confronted and addressed, rather than one subsuming or dominating the other. And they must ensure that theoretically-oriented work features strongly in applied health research: infusing research design, underpinning methodology and informing how data are analysed and interpreted.

Considerable progress has already been made in each of these areas. However, more could be done to ensure that when we do qualitative research we do it to the highest quality and are then confident in the value of our work. In doing so, we can then ensure that applied research is alive and kicking and with us for a long time to come.

^aThe Curious Incident of the Dog in the Night-Time, written by Mark Haddon and published by Vintage in 2004.

Poster presentations

001 PP

ONLINE CLINICAL MANAGEMENT PATHWAYS FOR CHLAMYDIA TREATMENT: ENRICHING FORMATIVE EVALUATION OF A COMPLEX E-HEALTH INTERVENTION

CRH Aicken,^{1*} CS Estcourt,² J Gibbs,² P Sonnenberg,¹ CH Mercer,¹ L Tickle,² LJ Sutcliffe,² ST Sadiq,³ M Shahmanesh¹. ¹University College of London, UK; ²Queen Mary University of London, UK; ³St George's University of London, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.12

Background Novel online clinical management pathways for chlamydia (eSexualHealthClinic) are being developed, enabling people to receive treatment remotely from clinical settings, with minimal contact with healthcare-professionals. Development follows Medical Research Council complex interventions guidance, and is iteratively informed by qualitative research.

In a mixed-methods pilot study, the eSexualHealthClinic is being explored for acceptability and preliminary evidence of effectiveness, among people who tested positive for chlamydia through conventional services. They receive test-results by text-message, and are offered online care. After completing an automated consultation, they can collect antibiotics from community pharmacies. If they prefer, or if medically appropriate, they are managed in clinic.

Objective To describe how the pilot study's qualitative component will deepen our understanding of its quantitative findings, further informing intervention development.

Methods Ongoing semi-structured follow-up telephone-interviews with people who used the eSexualHealthClinic, exploring views and experiences. Interviews are informed by the Theory of Planned Behaviour, also considering expectations and previous experiences of healthcare, emotional and contextual factors, themes from our previous qualitative research, and allowing emergent themes. Since prevention of transmission is paramount for infection control, reasons for delayed treatment are explored.

Contribution of qualitative research Interactions with the eSexualHealthClinic are time-logged, and participants are surveyed after completing care. These detailed quantitative data provide limited information on reasons for delays, (dis)

satisfaction, and unmet needs. Qualitative research enables in-depth, contextualised exploration of these issues, including influences on care-seeking unanticipated by researchers, which cannot be examined quantitatively.

Integration of qualitative and quantitative findings will enable participants' care-seeking behaviour to be more fully understood, informing care-pathway refinement, for maximum clinical and public health benefit.

Discussion Online healthcare is expanding. During development of novel web-based care-pathways, navigated with minimal supervision, understanding care-seeking behaviour through qualitative research is vital. This understanding is enhanced by mixed-methods design, where qualitative and quantitative research are mutually-enriching.

002 PP

TOWARDS AN ANTHROPOLOGY OF CARE: CANCER CARE PRACTICES IN THE EVERYDAY

MI Arteaga Pérez. *University College London, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.13

A patient affected by cancer is never alone with his/her disease; his/her social surroundings shape and are shaped by the daily practices aiming to manage the disease and its treatments. According to Macmillan Cancer Support report^a, informal caregivers of colorectal cancer patients tend to provide more hours per week of care than those supporting patients affected by other types of cancer (40% of them give at least 20 hours of care versus 25% of all carers). Such care usually requires performing multiple tasks, from emotional support, practical work to advocacy.

Psychosocial studies in oncology have successfully attended to the repercussions of cancer and cancer care in the family unit, emphasising the impact of such experiences and transactions for the mental and physical health of family members. In this abstract, I would like to contribute to that research by explaining how an anthropology of care can shed further light on these dynamics, unfolding the practical, cognitive and emotional aspects of care in the everyday contexts of people affected by cancer.

My argument is that an anthropology of care would illuminate: (1) the generation of embodied knowledge, emotion work and practical tinkering of caregiving practices by which requirements, side effects and consequences of colorectal cancer treatments are addressed, (2) the ways in which patients and their significant others negotiate the temporalities of treatments and the collective identities as supporters and patients during the day to day life, and (3) the ways in which social-cultural and political and economic arrangements shape people's experiences of cancer treatments.

^aMore than a million: Understanding the UK's carers of people with cancer—a report by Ipsos Mori for Macmillan Cancer Support.

003 PP

USING FOCUS GROUPS IN NATURALLY OCCURRING SETTINGS^a

S Brown. *Durham University, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.14

One of the strengths of focus groups is the insight they provide into participant interaction, which differs depending on whether participants are strangers or acquaintances. In this paper I reflect on experiences of conducting focus groups amongst

acquaintances in naturally occurring settings, where participants were known to each other and participation was less about being recruited, and more about being there when the focus group took place. I draw on data from field notes as well as from the groups themselves. I describe challenges and benefits of using naturally occurring groups, and reflect on the way the findings from these groups illuminated aspects of the study concerning relationships. I conclude by suggesting that using focus groups in naturally occurring settings alongside other qualitative data collection affords insights into the research topic that would not otherwise be available.

^aBrown S. Using focus groups in naturally occurring settings. *Qualitative Research Journal* 2015;15:86–97.

004 PP THE RESEARCHER IN RESIDENCE MODEL: GETTING EMBEDDED IN THE WELC INTEGRATED CARE PROGRAMME

L Eyre. *University College London, UK.*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.15

The Researcher in Residence model is a methodological innovation being developed by UCLPartners and Improvement Science London to help bring academic and practitioner communities more closely together to improve outcomes for patients and value for the health system. The model places the researcher as a key member of the delivery team rather than an external observer of change, and gives them a stake in the success, or otherwise, of the initiative. The expertise which the Researcher in Residence brings to the programme in which they are embedded is communicated to and negotiated with, rather than imposed on, the practitioners in the delivery team and other stakeholders.

The model is being applied in the Waltham Forest, East London and City (WELC) Integrated Care pioneer programme. The programme commissioned an embedded and process oriented local evaluation, which focuses less on whether the programme ‘works’ and more on how to use established research evidence to optimise the effectiveness of the implementation team. The WELC care collaborative has brought together commissioners, providers and local authorities covering the area served by Barts Health NHS Trust. The partners have come together to build a model of integrated care that looks at the whole person—their physical health, mental health and social care needs.

The overall aim of the WELC Integrated Care programme evaluation is to explore the processes by which integrated care is being implemented across WELC in order to enhance and improve the effectiveness of delivery of the programme objectives. The project has a strongly participative approach, underpinned by a critical realist ontology, an interpretive epistemology, and a Critical Discourse Analysis methodology.

005 PP THE BENEFITS OF USING QUALITATIVE RESEARCH METHODS TO UNDERSTAND CARE HOME MEDICINE MANAGEMENT SYSTEMS

JFM Gilmartin,^{1,2*} Y Jani,^{1,3} FJ Smith¹. ¹University College London School of Pharmacy, UK; ²Centre for Medicine Use and Safety, Monash University, Australia; ³University College London Hospitals NHS Foundation Trust, Pharmacy Department, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.16

In United Kingdom care homes (CHs), multi-compartment compliance aid (MCA) medicine management systems are more commonly used than original medicine packaging (OP), to organise and administer the large volume of medicines used by residents. This study aimed to understand how these two systems (MCAs and OP) impact on CH medicine administration.

This was a mixed methods study. The quantitative component involved direct observation to identify discrepancies in medicine administration. The qualitative component involved an ethnographic approach and interviews to understand the medicine administration process and identify associated barriers/facilitators. In September and October 2014, a pharmacist researcher spent 1–3 days observing 17 nurses administer medicines and interviewing 15 nurses, at 4 purposively sampled CHs around Greater London that used either MCAs or OP. Ethical approval was obtained from the University College London Research Ethics Committee.

The ethnographic approach allowed the researcher to immerse themselves into the work environment of the nurses. This facilitated a comprehensive understanding of the MCA and OP medicine management systems under research, at all times of the day and under all possible work conditions that could arise. The observations allowed the researcher to identify practices that may contribute to medicine administration discrepancies. These practices may not have been discussed at all, or in any great detail, during nurse interviews. Potential challenges of this qualitative research include participant apprehensiveness concerning the observations in general, or observations interfering with daily work practices. These were managed by ensuring observations were minimally intrusive and all participating CHs and nurses remained anonymous.

The qualitative research methods used in this study helped explain the quantitative data and provided a rich and comprehensive understanding of the systems under research, which is unlikely to have occurred using quantitative research methods alone.

006 PP LISTENING TO PARENTS: MIX-METHODS EVALUATION OF THE KEY WORKER ROLE

A Martins,^{1*} S Aldiss,¹ R Taylor,^{1,3} F Gibson^{1,2}. ¹London South Bank University, UK; ²Great Ormond Street Hospital for Children NHS Foundation Trust, UK; ³University College London Hospitals NHS Foundation Trust, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.17

Understanding how interventions work in the real world of practice has motivated the use of qualitative methods in evaluation of interventions in health care.^a A complex intervention may operate differently in practice from the original intention and qualitative research can address how an intervention is used in practice while quantitative research is used to measure outcomes.^b This paper describes the practical application of a mix-methods approach in the evaluation of a nurse specialist key worker role in children’s cancer care across the UK with reference to parents’ views of the role. Using this study as example, methodological issues are explored about the use of the interview/questionnaire approach in the evaluation, as well as a brief consideration of combining methods.

The nurse specialist key worker role was funded in eighteen Principal Treatment Centres across Scotland, Wales and England. Ninety parents took part in the questionnaire and out of these 20 took part in an individual semi-structured interview.

The information from the questionnaires helped identify the family's needs and the support received; it did not show, however, how contextual constraints and families' individual needs helped shape the way the key worker role was developed and the impact it had on families. The interviews allowed the researcher to pick up on these issues. In particular, the interviews expanded the breadth of understanding on how the key worker supported the families, what activities occurred under what conditions, and who carried out the activities.

The depth of the analysis and understanding of the impact of the key worker role was only achieved by the combination of methods used. The questionnaire allowed the evaluation of the role in specific outcomes and the interviews helped us identify and understand the influencing factors/conditions needed to achieve the outcomes.

^aO'Cathain A, Murphy E, Nicholl, J. Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. *BMC Health Services Research* 2007;7:85.

^bParry-Langdon, N., Bloor, M., Audrey, S., et al. Process evaluation of health promotion interventions. *Policy & Politics* 2003;31:207–16.

007 PP

COMBINED METHODOLOGY: DOING ETHNOGRAPHY WITH MULTI-SITED NARRATIVES

L Masana. *Universitat Rovira i Virgili, Tarragona, Spain*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.18

This poster focuses on the different ways—the combined methodology—I used to obtain data for my doctoral research on the experience and management of chronic illness in Spain of adults who are in the prime of their lives, and how I analyzed them. The lived experience of chronicity was explored through illness narratives in a multi-sited ethnography: interviews conducted in the homes of the participants; observation of a therapeutic group in a hospital and in a mutual help group in a patients' association; informal ethnography; autoethnographic books and scientific articles, secondary analysis of other published material; and several digital narratives about personal or collective experiences with diverse chronic conditions located on the Internet. The goal was to show the cultural circulation of meanings attributed to chronicity and the socio-cultural constructions of several chronic illnesses, which was achieved through a thematic analysis. For this purpose, a microsocial sample was chosen according to its significance and theoretically (not statistically) representative ethnographic value concerning the common denominator of a shared experience of chronicity. This combined methodology, which includes 'real' and 'virtual' narratives, oral and written narratives, and primary and secondary data, challenges us to rethink our concepts of data and our methodological approaches to the ethnographic field.

008 PP

BEYOND EFFECTIVENESS: CONDUCTING QUALITATIVE RESEARCH ALONGSIDE A CLUSTER RANDOMISED CONTROLLED TRIAL OF HIV TESTING IN GENERAL PRACTICE

H McMullen,^{1*} C Griffiths,¹ T Greenhalgh². ¹Queen Mary University of London, Department of Primary Care and Public Health, UK; ²Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.19

I worked as a trial manager of a cluster randomized controlled trial of rapid HIV testing in primary care settings over a 2.5 year period. This left me with a number of questions that were

unanswered by the trial design. I have since undertaken a PhD applying qualitative methodology to explore trial phenomena, including process evaluation, case study and qualitative interviews. We applied the Diffusion of Innovations in Healthcare Settings^a model to process data from the trial to explore high and low performing practices. This provided a rich picture of the intervention implementation process, as intended; however this data also prompted the need to revisit some of the assumptions upon which the trial was based. The trial assumed rapid testing would detect undiagnosed HIV however the exploration of patient data revealed this was not always the case. For example, already knowing their status, one patient used the rapid test to manage a number of factors related to their identity and personal circumstances, demonstrating the way testing and treatment creates meaning for patients. It also echoes what Annemarie Mol suggests in the Logic of Care, that we pay attention not only to what technologies are supposed to do, but what they happen to do.^b This example, among other unexpected findings, highlights the need for a greater theorisation of the data and the unravelling of trial assumptions. We explore the experience of conducting qualitative analysis alongside a cluster randomised controlled trial related to a stigmatised illness and discuss the challenges and insights gained in the process.

^aGreenhalgh T, Robert G, McFarlane F, et al. Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Quarterly* 2004;82: 581–629.

^bMol A. *The logic of care: health and the problem of patient choice*. London, United Kingdom: Routledge, 2008.

009 PP

EXPLORING CARERS' EXPERIENCES OF CARING FOR SOMEONE WITH ADVANCED DEMENTIA

KJ Moore,^{1,2,3*} E Ozanne,² B Dow,^{2,3} D Ames^{2,3,4}. ¹University College London, UK; ²The University of Melbourne, Australia; ³The National Ageing Research Institute, Australia; ⁴St Vincent's Health, Australia

*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.20

During advanced stages of dementia many people are no longer able to live independently at home. In Australia, home based case management packages were introduced for people with dementia and nursing home level care needs who wanted to remain at home. My PhD study aimed to develop a more in-depth exploration of carers' experiences of caring for someone with advanced dementia within the context of the formal service system. I undertook semi-structured interviews with carers who were eligible for a package (on a waiting list n=11; currently accessing a package n=14; accessed a package prior to their relative moving into a care home n=12; or prior to their relative's death n=1). As a PhD study I did not have a second researcher available to code and analyse data in depth. I was able to discuss themes and issues with my supervisors but this was not adequate for ensuring a rigorous analysis. I relied on participants to check my interpretation of the interview using summary reports. Participants were followed up three months after the interview to check whether their circumstances had changed and to reflect on the interview and report. This process proved to be useful as some participants made small clarifications about my interpretation while most indicated that the report was an accurate summary. For some, the report was enlightening and some commented that they appreciated having the opportunity to comment. The summary reports were used to identify themes which were then illustrated with quotes from transcriptions. This paper provides an approach to analysis that

aims to reduce the limitation of having a sole researcher analysing qualitative data. This study was undertaken at The University of Melbourne and the National Ageing Research Institute and was financially supported with an Assessment and Better Care Outcomes Dementia Collaborative Research Centre PhD scholarship.

010 PP

EXPLORING THE IMPACT OF A CANCER AWARENESS TRAINING PROGRAMME: A QUALITATIVE STUDY OF COMMUNITY-BASED HEALTH STAFF AND VOLUNTEERS

K Osborne,* E Power. *Cancer Research UK, UK*
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.21

Background Cancer Research UK's cancer awareness training programme, Talk Cancer, aims to equip and empower frontline healthcare staff and volunteers to raise awareness of cancer and promote health behaviour change in their community. Each workshop aims to increase knowledge of cancer prevention, screening and early diagnosis and improve confidence communicating with the public about these areas. This study evaluated the impact of workshops conducted across England between April 2013 and March 2014.

Methods Fourteen in-depth qualitative telephone interviews were conducted with attendees approximately four months after training. Interview transcripts were thematically analysed and themes independently verified by two researchers.

Findings After training, attendees reported increased awareness of the importance of early diagnosis and the link between lifestyle behaviours and cancer risk. They reported feeling more open towards cancer and that cancer had become a legitimate topic of conversation. They reported feeling more confident to have conversations about cancer and, for some, this was related to feeling more credible. As a result, attendees felt more able to manage and initiate conversations about cancer. Specifically, many attendees had promoted the importance of early diagnosis and encouraged people to seek help with an unusual or persistent change to their body. Some attendees also said they had visited the GP and made healthy lifestyle changes themselves.

Conclusions Talk Cancer training increased attendees' cancer awareness, openness towards cancer and confidence in having cancer-related conversations. In particular, attendees became advocates for prompt help-seeking after learning about the importance of early diagnosis. Furthermore, reports of attendees making changes to their own behaviour suggest the training may benefit attendees as well as their communities.

011 PP

FOOD-RELATED INTERVENTIONS IN DEMENTIA: A QUALITATIVE STUDY OF CAREGIVERS' PERSPECTIVES

I Papachristou,^{1*} G Hickey,² S Illife¹. ¹University College of London, UK;
²St George's University of London, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.22

As dementia progresses, caregivers increasingly have to manage the decline of food-related abilities with little intervention. The provision of food coping skills and knowledge can lessen the burden on caregivers. However, there is little research on

caregivers' perspectives on food-related interventions. This paper reports on a qualitative study to investigate informal caregivers' experiences of, and views on, food-related interventions in dementia. Twenty informal caregivers were interviewed and the transcripts from these interviews were analysed using both inductive and deductive thematic analysis. Three categories emerged. 'Direct food-related interventions', covers written material, training and lunch clubs 'Indirect non-food related interventions' covers respite services and domestic help at home. Finally 'No interventions' covers those who did not feel they needed any form of intervention due to confidence in managing food-related processes or having no change in dementia progression and food responsibility. Most caregivers will need different levels of education and support at different stages of dementia. It is necessary therefore to undertake ongoing individual assessment of food education and support needs. This study is the first to explore dementia and food-related social support and education needs and availability from the perspective of caregivers. A further, longitudinal study could investigate further the extent to which food-related interventional needs change over time. As dementia increases, caregivers seek more education and social support, therefore the timing of receiving this intervention is important to prepare caregivers in advance and to prevent negative outcomes occurring later.

012 PP

GOING BENEATH THE SURFACE IN A LONGITUDINAL QUALITATIVE NARRATIVE STUDY WITH YOUNG ADULTS WITH CANCER

S Pearce. *University College London Hospitals NHS Foundation Trust and the Cancer Institute, University College London, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.23

The impact of cancer on young people superimposed on the developmental processes toward adulthood is recognised (NICE 2005). Despite this there has been limited in-depth research to understand the experiences of young adults with cancer.

This study aimed to explore the issues that contribute to the impact of cancer, on young adults' evolving sense of self and identity, by listening to the stories of young adults over one year from the time of diagnosis.

This longitudinal narrative study was grounded in Ricoeur's (1984) notion of narratives as stories of experience. 18 young adults (16 to 30 years of age) took part in the study. Eight of the participants took part in three interviews over a year, 6 participants in two interviews. Data included conversational style interviews using free association; reflection of images taken; and detailed reflexive notes. Regular psychotherapeutic debriefing and an ongoing psychosocial research seminar group at the Tavistock Clinic created the space for reflection and awareness. Data were analysed longitudinally across individual cases; an integrated data framework from all the data was then developed.

One participant is used to illustrate the interplay between the psyche and the social, the internal and external worlds in the year from diagnosis to the end of life. This also illustrates the framework across all the data involving the renegotiation of self over time, expressed in narrative, through the core components of: the inner world, (psyche, emotion and coping); self as embodied; self as relating others, and self as relating to place.

This study demonstrates the value of storytelling over time for making sense, for patient centred practice and getting beneath the surface of experience. The importance of exploring both the

'said' and 'unsaid'; the challenge of 'being with' and 'standing alongside'; and the nature of psychosocial reflexivity all have important implications for empathic and compassionate care .

013 PP AN 'ENRICHED LANDSCAPE' OF QUALITATIVE RESEARCH: DIFFERENT APPROACHES TO THREE PUBLIC HEALTH ISSUES

D Romero. *Hunter College and the Graduate Center, City University of New York, School of Public Health, New York, USA*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.24

Qualitative methods have much to contribute to public health research. Below are three public health projects that provide a sampling of empirical research for reflection on the varied use of qualitative methods.

Collaborative Community Health Assessment St. Vincent's Hospital closed in 2010, resulting in loss of an ER, in-patient facilities, a trauma center, and outpatient clinics. There was great concern about potential gaps in health care. Romero et al worked with community partners, elected officials, health and social services providers, residents and others to collect data to assess the impact of the hospital closure, via focus groups, key-informant interviews and a community survey.

L-GEAR Project US rates of adolescent pregnancy are high among industrialized countries. There is a dearth of qualitative data from adolescents regarding life experiences, educational and career goals, and how their parents' own experiences might influence teens' attitudes and sexual behaviors. We are conducting in-depth interviews (IDIs) with adolescent girls, boys and their parents about their current life circumstances and future goals, and how sexual and childbearing behaviors factor into their lives.

Welfare Policy Analysis US welfare reform in the 1990s included state "child-exclusion" policies prohibiting additional cash assistance to families with a newborn. We conducted several studies to analyze the policy involving (1) IDIs of women subject to the policy; (2) review of effectiveness evaluations and content analysis vis-à-vis human rights treaties; (3) key-informant interviews with state welfare directors.

These three projects illustrate the wide range of qualitative research methods available to public health and other researchers, including in-depth and key-informant interviews, focus groups, and content analysis. It is clear that their combined use, including quantitative methods such as surveys, have much to offer to provide a deeper understanding of public health issues and related social programs and policies.

014 PP COUPLE SEXUALITY IN YOUNG ONSET DEMENTIA (THE COSY STUDY)

JN Symmonds,^{1*} T Whitfield,¹ A Pavitt,² R Ducksbury,³ L Lee,¹ Z Walker^{1,4}. ¹North Essex Partnership University NHS Foundation Trust, UK; ²University of East London, UK; ³University of East Anglia, UK; ⁴University College London, UK
*Presenting author.

10.1136/bmjopen-2015-UCLSymposiumAbstracts.25

Introduction Dementia is a devastating illness. The clinical criteria for dementia focus on cognitive and functional impairment. However patients' relationships are also affected, including their intimate and sexual relationships. These relationships are an

important part of an adult life, particularly in young adults and are part of a person's identity and self-esteem. A great deal of research has explored the impact of late onset dementia on couples' relationships. This study aims to explore the impact of young onset dementia (YOD) on intimate and sexual relationships.

Objectives (a) To explore the lived experiences of couples with YOD with regard to their sexual and intimate relationships; (b) To explore any issues in this area and to report what these problems are (for both the partner and the pwYOD); (c) To identify strategies that couples have found helpful in maintaining a close sexual and intimate relationship where one person has a diagnosis of YOD; (d) To identify issues frequently raised by study participants (as well as strategies/actions that have helped to maintain a close relationship) and (e) Use these issues to inform the development of an appropriate future clinical intervention. Where enough data is available, to relate the findings to: (i) The severity of the pwYOD's illness; (ii) The type of dementia; (iii) Gender and (iv) The type of relationship the couple had before the pwYOD developed dementia.

Methods We are in the progress of interviewing patients and their partners, with the plan to recruit in total 10–20 individuals from 8–12 couples. We have completed five interviews with further interviews planned for the near future.

Interviews will be transcribed and thematically analysed. To date, interviews have highlighted important challenges and needs, including the setup of group, individual, and couple interventions.

015 PP A LONE VOICE: REFLECTIONS ON PRESENTING QUALITATIVE RESEARCH AT A SURGEON'S CONFERENCE

D Trusson. *University of Nottingham, UK*

10.1136/bmjopen-2015-UCLSymposiumAbstracts.26

In this paper I describe how I used my dual position of service user and sociologist to present my research findings at an international conference for surgeons. As a former breast cancer patient I was invited to participate in a study of women's experiences of having breast reconstruction using their own body tissue. Questions included rating my happiness and confidence on a scale of 1–10 which challenged me as a qualitative researcher. The study also revealed parallels with my own research with 24 women who had been treated for early stage breast cancer, where similar issues had emerged organically through their narratives. When I discussed this with the breast care team I was encouraged to submit an abstract to the conference where the results of the quantitative study were going to be presented.

The subsequent paper, entitled 'Autologous Breast Reconstruction from the Patient's Perspective: A Qualitative Study,' was presented at the 5th International Meeting of Oncoplastic and Reconstructive Breast Surgery in Nottingham in September 2013.

My reflections on my experience of presenting to an audience, who were unaccustomed to qualitative research, include the challenges of facing my own intimidation by health professionals as a patient. I will discuss the positive feedback that I received which will hopefully encourage other qualitative health researchers to reach beyond the usual audiences in order to disseminate their research findings.