Engaging with Users and Stakeholders: The Emotional and the Personal

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ABSTRACT

HCI and CSCW researchers and practitioners are increasingly working in complex social and political contexts where their research activities involve emotional labor and where they have to confront moral and emotional dilemmas. Given the potential impact of these challenging situations on the wellbeing of researchers in the field, there is much need for a discourse on affective impact of research on the researcher. In this workshop, we invite discussion and reflection on the experiences of distress and the role of *informal coping mechanisms* (e.g., personal narratives) to address them. We will create a forum where researchers and practitioners can discuss and share experiences of projects in sensitive settings and work towards guidelines to inform future projects.

CCS Concepts

• HCI design and evaluation methods • accessibility theory, concepts and paradigms

Keywords

Methodology; reflection; validity; participatory design; user-centered design, qualitative research; emotion; sensitive settings; ethics; disability; aging; marginalization.

1. WORKSHOP THEME

Previous research by has shown that when confronted with emotional or moral dilemmas, researchers in our field are often left to their own devices [11]. Whereas in other fields, such as psychology and nursing, formalized strategies, such as reflection, counseling and peer-support, exist to support the emotional well-being of researchers, researchers in the field of HCI/CSCW oftentimes have to rely on their own devices to cope with these issues. In the absence of formal or institutional mechanisms of support, researchers have to rely on personal empathic and trusting relationships with supervisors and peers [11].

All the while, CSCW/HCI researchers and practitioners are increasingly conducting projects that involve them at an emotional level and impact their "moral universe" [23]. Examples of such projects include research conducted in socially and politically volatile settings, such as in refugee camps [27] or low-income settings [7], and in other *sensitive settings* where stakeholders are emotionally vulnerable, such as in bereavement support [2, 5], technology development for children and adults with disabilities [8, 9, 19] and support for the aging population [1,14] and in home care settings [18, 21].

The importance of this topic is increasingly being recognized. For example, Lindsay et al. have discussed the importance of empathy when working with the elderly [10]. Crabtree et al. have discussed different methodological challenges when researching with persons with mental illnesses [3]. Other work has described challenges when conducting research with persons suffering from dementia [4]. While these research projects address important questions by placing vulnerable target groups at the center of the discussions, there is a shortage of research when it comes to the emotional involvement of the researchers themselves in these interaction settings. Examples of existing research include discussions of autoethnographic approaches in the design for the elderly [22] and in bereavement support [25]. In addition, Rode has explored the concept of "rapport", where in the context of research on gender specific appropriation of technologies in a family household, she reflected on her own behaviour as an adaption to female roles as perceived by the family members in order to set up a deeper relationship to her research partners [16]. Similar discussions on the impact of socially-constructed notions of disability and aging, for example identifying them with illness, weakness and neediness, and their impact on the process and outcome of research efforts have emphasized the importance of confronting and deconstructing assumptions as a part of research activity [12, 17] There is still a lack of discussion and reflection on the more "human" aspects of the researcher's experience and how to tackle these issues with respect to the scientific method.

The objective of this workshop is to provide a forum for research concerning the issue of *affective impact on the researcher* who, in the context of HCI or CSCW user-centered design or research, develop close empathic and trusting relationships with stakeholders in such settings [26]*;* engagements that often entail emotional labor, which, in turn, may generate distress [13]. Reflection on these aspects of our own culture of research has an established precedence [6, 24]. This workshop is intended to complement the existing body of work and to provide new directions of inquiry and new modes of engagement with its topic area. In particular, this workshop, in addition to providing a venue for scholarly work, will create an explicit space for the *personal narrative*.

GROUP '16, November 13-16, 2016, Sanibel Island, FL, USA
ACM 978-1-4503-4276-6/16/11.
http://dx.doi.org/10.1145/2957276.2996292

The use of personal narratives — both as tools for empathic self-reflection [26] and as informal coping mechanisms [20] — has been noted in previous research. We invite a discussion on how personal narratives and other forms of self-expression can be used as a coping tool to express concerns one has as a researcher or practitioner when working in sensitive settings or in relation to personal conflicts and tensions between the researcher role and the "human" side of research. A key challenge is how to address concerns about privacy (both participants and researcher) and security when sharing such sensitive material. Another related question is how can researchers/practitioners share narratives about project failures or about challenging situations (i.e., "war stories" [15]) without fear of being perceived as "weak" or "unprofessional". In contrast to other fields of research, such as Sociology, where researchers focus on observing, describing and understanding social actions and dynamics, HCI and CSCW researchers mostly aim to apply their research to create or modify technology that intervenes or at least changes something in the world. The applied nature of the research field might add additional emotional and moral pressures on the researcher. A similar discourse is currently underway in the medical field in Germany with respect to a lack of a "culture of failure", where practitioners can share examples where they failed in their practice without risking being perceived as incompetent. A suggested solution has been the creation of an online form where personal narratives can be shared and discussed anonymously (www.kritische-ereignisse.de, translation: "critical incidents"). A question is how can we translate elements of similar discourses for our own field.

Previous reflection on these aspects of our own culture have largely viewed emotional impact through the lens of *ethics*, a perspective that is indeed important, in order to systematize concepts of "right" and "wrong" actions and behaviors in researchers in these sensitive settings [6, 24]. For the proposed workshop, we adopt a complementary, intra-personal stance, and ask: what is subjectively experienced and felt, and what is one's reaction to it? We aim to complement the existing body of work and to provide new directions of inquiry and new modes of engagement with its topic area. Our focus, in this workshop, turns towards experiences of distress and the role of *informal coping mechanisms* (vis-a-vis institutional practices), such as the use of *personal narratives,* to address them and provide a form of sense-making.

2. WORKSHOP OBJECTIVES

The objectives of the workshop are threefold:

Contributions to the body of knowledge: to further characterize the phenomena of intra-personal affective impact in sensitive setting research; to identify existing practices and to reflect upon them; to forefront and to discuss culturally-embedded tropes and imagery that may be active within the field (e.g., concerning ageing, disability, mortality) and the impact of these tropes on the researcher's own emotions; to discuss the potential contribution of emergent theories, including the social and post-modern models of disability and third wave HCI to this field; to deconstruct and reflect upon transdisciplinary, inter-organizational project work.

Impact on Research Culture: to provide a forum to share experiences in conducting research in sensitive settings and to discuss the features, challenges and rewards of working in such settings; to open up a space for discussion and reflection of such sensitive themes, to identify processes for bringing mindfulness and self-reflection to the research process; to deconstruct socially constructed notions about affective impact which oftentimes are conflated with a "weakness" in the researcher.

Methodological: to create and to disseminate a set of guidelines/best practices for conducting research in sensitive settings, including how they can translate to hands-on training of researchers and practitioners new to this area; to develop instruments for investigation of this theme in the longer-term (e.g. a repository of anonymous personal narratives in the form of a website).

In order to collaboratively attain these goals, we invite discussion on the following questions:

- What can we learn from experiences from successful and unsuccessful projects in sensitive settings that inform better approaches in the future?
- How can we build a repertoire of qualitative case studies and empirically grounded concepts to inform HCI practice in sensitive settings?
- How can we adopt holistic and inclusive approaches to topics such as aging, disability and social marginalization and apply them to activities in the field?
- How can our understanding of the constructed notions of disability and aging translate to other contexts such as working with children and adults living in low-income and/or marginalized contexts?
- How can researchers and practitioners better prepare themselves to resolve emotional and personal encounters in the field?

3. WORKSHOP DESCRIPTION

3.1 Call for Participation

This workshop is intended to solicit participation from HCI and CSCW researchers and practitioners. It is our desire to solicit participants from different communities, with various backgrounds and levels of experience, in order to foster inter- and transdisciplinary discussions. Intended participants include academics, industrial researchers and designers with experience working in sensitive and complex settings. We also encourage the participation of graduate trainees and early researchers.

Our call for participation will be an invitation for contributions for position papers and personal narratives, including autoethnographic accounts related to the workshop theme, including new related perspectives not covered in the workshop objectives and questions.

Position papers: scholarly works, theoretical, conceptual, or empirical, which address the theme of the workshop. Submissions of autoethnographic accounts that include personal narratives (see below), as well as reflection pieces are encouraged. Authors of accepted position papers will present in the workshop sessions. Submissions in this category must have a maximum length of 4 pages (this format), including references.

Personal narratives: first-person accounts, which address the theme of the workshop in a subjective manner and engage in reflection. Care should be taken in such narratives for proper de-identification. Authors may anonymize their narratives. Accepted personal narratives will be published on the workshop website and in archival materials, and may be drawn upon by participants during the workshop session. Authors of accepted personal narratives are welcome to participate in the workshop, but are not obliged to do so. Submissions in this category must have a maximum length of 2 pages (this format).

3.2 Workshop Format

A full-day workshop is planned that will consist of five sessions (coffee break between session 2 and 3, lunch break planned between session 3 and 4): Session 1 (am): organizers provide an introduction to the theme and topics of the workshop

Session 2 (am) and Session 3 (am): position paper presentations by the participants (10-15 minutes each) with opportunity for (audience discussion/Q&A).

Session 4 (pm): This session will consist of small group (3-4 person) discussions. The participants will discuss the presented papers using a theme identified in the morning sessions. The organizers will pre-plan a set of discussion themes, and will augment with emergent material from the morning sessions.

Session 5 (pm): In this session, each team will present an overview of their discussion to the whole group. The session will conclude with a reflective discussion followed by a summary of the insights that emerged during the workshop. We will work towards generating a set of guidelines pertaining to advice on how researchers and practitioners can better prepare themselves to resolve ethics and emotional encounters in the field.

We require space for 10-15 participants, with reconfigurable seating (to support the break-out discussions). The workshop will also require a projector and Internet connectivity. The organizers will identify additional requirements (e.g., accommodation for service animals, scent-free environment, etc.) that might arise due to accommodations required by participants as they emerge.

3.3 Outreach and Selection Process

Materials for the workshop will be hosted on a workshop website through which advertising, submission, distribution of reading material and organization will be handled. Archival material from the workshop will also be hosted on the website. The workshop's call for participation will be announced on a variety of mailing lists (e.g., from CHI and CSCW communities).

The workshop organizers will review the position papers and select 10-15 papers based on degree of originality and potential to stimulate discussion. Personal narratives are understood to be creative works and will be selected according to criteria of originality, potential for impact, and writing caliber. They will also be reviewed to ensure participant privacy is preserved.

3.4 Post-Workshop Dissemination

We intend to disseminate the workshop outcomes on the workshop website. In addition, accepted workshop papers will be published in a special issue of IRSI (International Reports of Socio-Informatics) or another HCI- or CSCW-related journal. Authors of selected papers will be invited to submit their workshop paper (with the opportunity for elaboration) to this peer-review process. We will discuss other possible options for dissemination with participants at the conclusion of the workshop. We plan to have a follow up workshop in the future on the basis of the outcomes from the current proposed workshop.

4. ORGANIZERS

Dr. Foad Hamidi's research interests include community-engagement and Participatory Design with children and adults with disabilities and their parents, caregivers and teachers. He received his doctorate in Computer Science at the Lassonde School of Engineering at York University, where he has designed and evaluated several systems for children including a living media system to motivate children to use more learning and therapeutic systems, and a DIY communication board system for non-verbal users. He is also interested in intercultural collaboration and has been of transnational teams working on projects in Africa and Central America.

Dr. Claudia Müller is an assistant professor at the department of information systems at University of Siegen, Germany, with focus on "IT for the ageing society". With a background in cultural anthropology, medical history and medical ethnology, Claudia subsequently follows a socio-cultural perspective on the development and appropriation of new technologies in home care and everyday contexts since many years. Her particular research interest is in developing appropriate research methods for co-designing with technology non-affine persons, e.g. to adapt the Living Lab methodology to the respective contexts.

Dr. Melanie Baljko is a research scientist working at the intersection of computing and the human. She is an Associate Professor of Electrical Engineering and Computer Science, holds a joint appointment to Department of Science and Technology Studies at York University, and is an Affiliate Scientist at the UHN-Toronto Rehabilitation Institute. She is a critical technology practitioner with interests in digitally-mediated social engagement, and assistive and rehabilitation technologies.

Marén Schorch is a research associate and leader of the EU-project TOPIC (The Online Platform for Informal Caregivers) at the University of Siegen, Germany. In this project, her research is focused on ethnography with elderly, informal caregivers in a rural area in Germany and the collaborative development of an information and support platform. She holds Master's degrees in Sociology and Psychology and worked as a research assistant and lecturer in Sociology and qualitative social research methods at the Universities of Trier and Bielefeld, Germany. Her main research interests and publications are in qualitative social research, biographies and identity, focusing on the way people deal with extreme events, health and sickness.

Dr. Myriam Lewkowicz is Full Professor in Informatics at Troyes University of Technology (France), where she is head of Information System Management teaching branch and Tech-CICO research group (part of UMR CNRS 6281). Her research focuses on designing systems for social interactions. It consists in defining innovative platforms to support existing collective practices or to design new collective activities. Her research is clearly interdisciplinary, and leads to reflections and propositions for new approaches which help defining new devices and services. For 10 years now, her main application domain is healthcare, with several projects at the regional, national and European levels. Myriam Lewkowicz is Program Committee Member of the main scientific conferences in CSCW and CHI (CSCW, CHI, ECSCW, COOP, GROUP, Communities&Technologies), and founding member of the ActiveAgeing Living Lab.

Abigale Stangl is a doctoral student at the ATLAS Institute at the University of Colorado-Boulder, USA, and research assistant with the Sikuli Lab in the Department of Computer Science. Her research interests include how people design, distribute and contribute to a growing body of accessible media and assistive technologies. Through participatory methods, she facilitates and assesses learning experiences that engage people of all abilities in Do-It-Yourself assistive technology design, and fabrication and learning and multi-modal literacy activities. She holds a Masters of Sciences in Information Communications Technology for Development (ICTD) from the ATLAS Institute at CU-Boulder, a graduate diploma in Landscape Studies from Lincoln University, and a Bachelors of Environmental Design from CU-Boulder.

5. REFERENCES

[1] Alaoui, M., Lewkowicz, M. 2015. Practical issues related to the implication of elderlies in the design process. The case of a Living Lab approach for designing and evaluating social TV services. *IRBM Journal Innovation and Research in BioMedical Engineering*, 36 (5), 259-265.

[2] Baljko, M. 2016. Technology-mediated community: the digital, the interactive and commemorative tattoo practice. In *The Tattoo Project: Creating a Digital Archive for Commemorative Tattoos*. Davidson, D. (Ed.). Canadian Scholars' Press.

[3] Crabtree, A., Hemmings, T., Rodden, T., Cheverst, K., Clarke, K., Hughes, J. and Rouncefield, M. 2003. Designing with care: Adapting cultural probes to inform design in sensitive settings, In *Proc. of the Australian Special Interest Group for Computer Human Interaction,* 4-13.

[4] Dahl, Y. and Holbø, K. 2012. Value biases of sensor-based assistive technology: case study of a GPS tracking system used in dementia care. In *Proc. of the Designing Interactive Systems Conference*, 572-581.

[5] Davidson, D., Baljko, M., and Letherby, G. 2012. Griefwork online: Community through computer-mediated communication. In *Proc. of the Motherhood Initiative for Research and Community Involvement Conference*. Toronto, Canada.

[6] Davis, H. and Waycott, J. 2015. Ethical Encounters: HCI Research in Sensitive and Complex Settings. In *Proc. of the Australian Special Interest Group for Computer Human Interaction,* 667-669.

[7] Hamidi, F., Saenz, K., and Baljko, M. 2014. Sparkles of brilliance: incorporating cultural and social context in codesign of digital artworks. In *Proc. of the Conference on Interaction Design and Children,* 77-84.

[8] Hamidi, F., Baljko, M., Ecomomopoulos, C., Livingston, N. J., and Spalteholz, L. G. 2015. Co-designing a speech interface for people with dysarthria. *Journal of Assistive Technologies*, *9*(3), 159-173.

[9] Hamidi, F., Baljko, M., Kunic, T., and Feraday, R. 2015. TalkBox: a DIY communication board case study. *Journal of Assistive Technologies*, *9*(4), 187-198.

[10] Lindsay, S., Brittain, K., Jackson, D., Ladha, C., Ladha, K. and Olivier, P. 2012. Empathy, Participatory Design and People with Dementia. In *Proc. of the Conference on Human Factors in Computing Systems,* 521-530.

[11] Moncur, W. 2013. The emotional wellbeing of researchers: considerations for practice. In *Proc. of the Conference on Human Factors in Computing Systems,* 1883-1890.

[12] Mankoff, J., Hayes, G. R., and Kasnitz, D. 2010. Disability studies as a source of critical inquiry for the field of assistive technology. In *Proc. of the Conference on Computers and Accessibility*, 3-10.

[13] Mitchell, W., and Irvine, A. 2008. I'm okay, you're okay?: Reflections on the well-being and ethical requirements of researchers and research participants in conducting qualitative fieldwork interviews. *International Journal of Qualitative Methods*, *7*(4), 31-44.

[14] Müller, C., Neufeldt, C., Randall, D., and Wulf, V. 2012. ICT-development in residential care settings: sensitizing design to the life circumstances of the residents of a care home. In *Proc. of the Conference on Human Factors in Computing Systems*, 2639-2648.

[15] Orr, J. E. 1990. Sharing knowledge, celebrating identity: Community memory in a service culture. *Collective remembering*, *169*, 189.

[16] Rode, J. A. 2011. Reflexivity in digital anthropology. In *Proc. of the Conference on Human Factors in Computing Systems*, 123-132.

[17] Rogers, Y., and Marsden, G. 2013. Does he take sugar?: moving beyond the rhetoric of compassion. *Interactions*, *20*(4), 48-57.

[18] Schorch, M., Wan, L., Randall, D. and Wulf, V. 2016. Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers. In *Proc. Conference on Computer-Supported Cooperative Work & Social Computing*, 787-799.

[19] Stangl, A., Hsu, C. L., and Yeh, T. 2015. Transcribing Across the Senses: Community Efforts to Create 3D Printable Accessible Tactile Pictures for Young Children with Visual Impairments. In *Proc. of the Conference on Computers & Accessibility*, 127-137.

[20] Taylor, S. E., Aspinwall, L. G., Giuliano, T. A., Dakof, G. A., and Reardon, K. K. 1993. Storytelling and Coping With Stressful Events. *Journal of Applied Social Psychology*, *23*(9), 703-733.

[21] Tixier, M. and Lewkowicz, M. 2015. Looking for Respite and Support: Technological Opportunities for Spousal Caregivers. In *Proc. of the Conference on Human Factors in Computing Systems,* 1155-1158

[22] Tonolli, L., Teli, M., and D'Andrea, V. 2015. A Design Anthropology Critique of Active Aging as Ageism. *Interaction Design and Architecture(s) Journal*, 26: 95-113.

[23] Wan, L., Müller, C., Wulf, V., and Randall, D. W. 2014. Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In *Proc. of Conference on Human Factors in Computing Systems*, 3987-3996.

[24] Waycott, J., Davis, H., Thieme, A., Branham, S., Vines, J., and Munteanu, C. 2015. Ethical encounters in HCI: Research in Sensitive Settings. In *Proc. of the Conference EA on Human Factors in Computing Systems*, 2369-2372.

[25] Woodthorpe, K. 2007. My life after death: connecting the field, the findings and the feelings. *Anthropology Matters*, *9*(1).

[26] Wright, P., and McCarthy, J. 2008. Empathy and experience in HCI. In *Proc. of the Conference on Human Factors in Computing Systems*, 637-646.

[27] Wulf, V., Aal, K., Abu Kteish, I., Atam, M., Schubert, K., Yerousis, G., Randall, D., and Rohde, M. 2013. Fighting against the wall: Social media use by political activists in a Palestinian village. In *Proc. of the Conference on Human Factors in Computing Systems,* 1979-1988.