Lost in translation: will the 'personal' become 'impersonal' when conducting research in the age of technology?

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As new technology permeates the research process, could the personal touch be lost in translation? When conducting research, its success is dependent upon the relationships established between the investigator, their research team and the study participants. Penckofer, Byrn, Mumby and Ferrans identify factors often associated with successful recruitment and retention of study participants, including advertising through branding, monetary incentives, convenient times and the altruistic nature of individuals [1]. They emphasize, however, that the single most important factor in subject accrual and participation is the relationship(s) the participant establishes with the study personnel during their research experience. Using 'Peplau's Theory of Interpersonal Relations', they address the three phases of the relationship that develop as the study participant engages in the research process [2]. The first phase called the 'orientation phase' occurs when the participant has their first encounter with the study personnel, most often a nurse. It is during this time that the participant is informed about the intent of the study and has a discussion about the risks and benefits (if any) of the study prior to signing the informed-consent document. It is also during this time that trust is established between the participant and the study nurse. The orientation phase occurs most often during a face-to-face experience and, as described by Peplau, it is during this time that "knowing the individual needs of the person, the nurse helps to establish caring interactions that are necessary for the relationship" [1].

Trust is essential for the participant to proceed into the 'working phase' of the relationship. This can be the time during which the participant engages in the activity of the study (e.g., the treatment or control) and where he/she "may learn about their current health condition, understand their condition and identify what is required for them to care for themselves" [1]. During this phase, it is important that communication continues between the participant and nurse to maintain their relationship. It is possible that as respondent burden increases (frequent data collection points); more contact is needed by the nurse to address participant concerns and/or maintain their engagement in the protocol. These interactions are often face-to-face, but may also be conducted by telephone, particularly for longitudinal studies. It is during this phase that the nurse may be challenged as she experiences conflict in her role as a 'study nurse' rather than as a nurse who is 'providing care'. This conflict may or may not influence the trusting relationship that has been established (e.g., not able to disclose information due to study protocol). However, if the role performed by the nurse is not congruent with the study protocol, it can impact on the integrity of the study itself [3].

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Finally, as the study approaches closure, the final phase of the relationship called, the 'termination phase', begins. It is during this phase that "it is important to provide sufficient time to allow individuals to express their feelings about termination" [1]. There is a reflection upon the events that have taken place over the course of the study and how to proceed forward. Often, a participant is referred to their primary care provider where a treatment may continue or may be offered to the participant – if not previously offered during the study. The final meeting during this phase most often occurs face-to-face so emotions can be seen and shared between the participant and the study nurse. It is during this time that gratitude is expressed to the participant for their time, effort and, most importantly, for their contribution to the development of science.

Peplau expressed concern that in the 21st century, human relationships could become 'impersonal' as recorded messages replace a personal phone call and virtual reality replaces reality [2]. Although she did not address the concept of texting and Facebook, these are the methods currently being used by over 73% of teens and young adults in establishing and continuing relationships [4]. There has been a shift as the norm has become a 'text message' rather than a personal phone call and a 'Facebook newsfeed' has replaced the enlightening conversations held by close friends over coffee or dinner.

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These forms of engagement are now being used by investigators to disseminate information to their team members as well as study participants. Previously, researchers using the internet for accrual of participants demonstrated mixed success using this recruitment method [5,6]. More recently, however, using Facebook for the recruitment and retention of study participants has suggested success [7–11]. Similarly, the use of the internet for delivery of study interventions [12] was once considered novel and now social-networking sites for health research [13] and Twitter for data collection [14] by mobile devices are innovative. The implications to the research community are significant [15–17], particularly as they relate to the personal aspect of the relationship of the study participant to the research personnel [1,18,19].

What will remain to be seen is whether the use of advanced technology that requires less personal face-to-face contact will influence the recruitment of the type of participants (age, gender, race, ethnicity or disease states), as well as their reason for participation (altruistic, monetary or seeking treatment). Will recruitment attract persons who have never engaged in research? For example, those who may have seen a recruitment flyer and passed by, now view a colorful sophisticated animation that piques their interest to participate. Those who lived in remote areas and could not participate in research may be able to do so by mobile applications. What is uncertain is whether these participants will be different from those who may have participated in studies that used a more personal interaction (face-to-face). If these participants are different, will the outcomes be different? And, if the outcomes are different, will we be able to use previous research as comparisons given that the method for data collection is so different? Will study retention improve as text-message reminders are viewed by the participant immediately as the personal letter reminding them about their appointment sits on the table at home, waiting to be opened at the end of the week? Once enrolled, will participants who engage in an intervention using virtual reality have different needs and expectations than a group with face-to-face intervention? Will they view it as a personal or impersonal experience due to the lack of the physical presence of another individual? Will participants long for the personal contact of someone concerned about their study progress? As the study nears completion, will participants have an understanding that this relationship (whether perceived as personal or impersonal) is about to terminate? Will that termination be easier or more difficult for participants who use technology as their method of engagement?

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There is no doubt that technology will significantly influence the manner in which we conduct our research and the manner in which we engage our study participants. Although there may be a period of disruption as these new technologies are developed, tested and refined for the conduct of research, we should never forget that the study participant is the single, most important part of the process. For without their commitment, clinical research cannot be conducted or new knowledge generated. Thus, it will be essential that the 'personal' experience be carefully translated into what may become an 'impersonal'

process. As researchers, it will be necessary to ensure that the personal process is maintained so that the technology used to advance science does not thwart it. Will the personal touch be lost in translation? It will ultimately be up to the scientific community.

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References

1 Penckofer S, Byrn M, Mumby C, Ferrans CE. Improving subject recruitment, retention and participation in research through Peplau's theory of interpersonal relations. *Nurs. Sci. Q.* 24(2), 146–151 (2011).

2 Peplau H. Peplau's theory of interpersonal relations. *Nurs. Sci. Q.* 10, 162–167 (1997).

3 Jack S. Guidelines to support nurse-researchers reflect on role conflict in qualitative interviewing. *Open Nurs. J.* 2, 58–62 (2008).

4 Lenhart A, Purcell K, Smith A, Zickuhr K. *Social Media and Mobile Internet Use Among Teens and Young Adults.* Pew Intenet & American Life Project, Washington, DC, USA (2010).

5 Koo M, Skinner H. Challenges of internet recruitment: a case study with disappointing results. *J. Med. Internet Res.* 19(7), e6 (2005).

6 Bull SS, Vallejos D, Levine D, Ortiz C. Improving recruitment and retention for an online randomized controlled trial: experience from the Youthnet study. *AIDS Care* 20(8), 887–893 (2008).

7 Ramo DE, Prochaska JJ. Broad reach and targeted recruitment using Facebook for an online survey of young adult substance use. *J. Med. Internet Res.* 14(1), e28 (2012).

8 Fenner Y, Garland SM, Moore EE *et al.* Web-based recruiting for health research using a social networking site: an exploratory study. *J. Med. Internet Res.* 14(1), e20 (2012).

9 Richiardi L, Pivetta E, Merletti F. Recruiting study participants through Facebook. *Epidemiology* 23(1), 175 (2012).

10 Jones L, Saksvig BI, Grieser M, Young DR. Recruiting adolescent girls into a follow-up study: benefits of using a social networking website. *Contemp. Clin. Trials* 33, 268–272 (2012).

11 Mychasiuk R, Benzies K. Facebook: an effective tool for participant retention in longitudinal research. *Child Care Health Dev.* doi:10.1111/j.1365-2214.2011.01326.x (2011) (Epub ahead of print).

12 Couper MP, Alexander GL, Zhang N *et al.* Engagement and retention: measuring breadth and depth of participant use of an online intervention. *J. Med. Internet Res.* 12(4), e52 (2010).

13 Selkie E, Benson M, Moreno M. Adolescents' views regarding uses of social networking websites and text messaging for adolescent sexual health education. *Am. J. Health Educ.* 42(4), 205–212 (2011).

14 Schembre SM, Yuen J. Project TwEATs: a feasabliity study testing the use of automated text messaging to monitor appetite ratings in a free-living population. *Appetite* 56(2), 465–468 (2011).

15 Glickman SW, Galhenage S, McNair L *et al.* The potential influence of Internet-based social networking on the conduct of clinical research studies. *J. Empir. Res. Hum. Res. Ethics.* 7(1), 71–80 (2012).

16 Swan M. Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *J. Med. Internet Res.* 14(2), e46 (2012).

17 Paradise A, Sullivan M. (In)visible threats? The third-person effect in perceptions of the influence of Facebook. *Cyberpsychol. Behav. Soc. Netw.* 15(1), 55–60 (2012).

18 Graziotti AL, Hammon J, Messinger DS *et al.* Maintaining participation and momentum in longitudinal research involving high risk families. *J. Nurs. Scholarsh.* doi:10.1111/j.1547-5069.2012.01439.x. (2012) (Epub ahead of print).

19 Kost RG, Lee LM, Yessis J, Coller BS, Henderson DK. The Research Participant Perception Survey Focus Group Subcommittee. Assessing research participants' perceptions of their clinical research experiences. *Clin. Transl. Sci.* 4(6), 403–413 (2011).