*Probe*lems: reflecting on a technology probe into peer involvement in cardiac rehabilitation

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Abstract— **Given the widely acknowledged impact that social support has on health outcomes, we set out to investigate peer-involvement in cardiac rehabilitation and explore the potential for technological support thereof. We planned to deploy a purpose built technology probe into a 10–week rehabilitation program. This paper presents the findings of the probe's pilot study, where rejection of technology and reluctance to involve peers highlighted important considerations for the design of peer-based health promotion technologies and methodological considerations for the study of peer-involvement in behavioural change as well as pervasive health research in general.**

Keywords: behavioural change, social support, social computing, physical activity, cardiac rehabilitation, early adopters, technology probe

I. INTRODUCTION

Social support is widely acknowledged as having a positive relationship with many health related outcomes, including recovery from heart attacks [1]. Within rehabilitation, social support is considered a resource for behavioural change [2]. Despite such wide acknowledgement, understanding of the underlying mechanisms and dynamics of social support is lacking. Non-clinical studies of multi-user activity promotion systems, including our own, have generated diverse and sometimes conflicting results [3,4,5,6].

Our work investigates peer-involvement within various behavioural change domains — such as weight management [7], preventative health [6,8] and cardiac rehabilitation — while exploring the potential for supportive technological interventions; systems to support *appropriate* peer involvement in behavioural change. We aim to determine the information needs of individuals and their peers, and to discover what level of involvement the involved parties feel is appropriate. By discovering how, when, why and with whom people wish to share change-related information, steps can be taken towards developing technological means of supporting the different levels and dimensions of peer involvement and social support [2].

We set out to investigate peer-involvement in cardiac rehabilitation through the deployment of a purpose built technology probe, Collabohab. This paper documents the 'problems and issues' that were faced during the pilot study that highlight potential obstacles to the feasibility of utilising social networking technologies within this domain. We will start with a brief description of Collabohab, before focusing on obstacles relating to both technology and behavioural change itself. The paper ends with our plans for the main study, our preliminary design suggestions, and a discussion of the implications for future work in this area.

II. METHOD

The use of technology probes [9] within the health domain is inarguably in its infancy, but they have proved to be a promising medium through which to study practices not easily observable e.g., self-management practices of individuals with diabetes [10] and the adoption process of assistive technology [11]. We therefore thought that they provide an ideal medium through which to study the complex area of social support within rehabilitation programmes: an area that covers geographically and temporally disparate phenomena.

A. Collabohab

The purpose of Collabohab was to create a medium through which rehabilitation-related data could be captured and explicitly shared with, or hidden from, peers. Of particular interest are patterns of interaction that exist between rehab participants and specific members of their friends and family, followed by interaction between fellow rehabilitation participants. If identifiable patterns did emerge, we wanted to find out if they persist throughout the rehabilitation process or whether they change over time.

The design of Collabohab was informed by a series of meetings with the management of the rehabilitation service, including the head nurse and head physiotherapist. Collabohab is a multimedia rehabilitation journal which provides participants with the ability to share their experiences with their peer group (fellow rehabilitation participants and invited friends and family). Essentially, Collabohab has three core functionalities facilitated by a mobile phone and web-based component:

- Self-monitoring of behavioural and physiological risk factors (manually entered via mobile interface)
- The capturing of experiential aspects of rehabilitation in the form of photographic, audio and video 'memoirs' (via mobile interface)

Digital Object Identifier: 10.4108/ICST.PERVASIVEHEALTH2009.6010
http://dx.doi.org/10.4108/ICST.PERVASIVEHEALTH2009.6010

- Information captured on the mobile phone is also uploaded to a web journal that provides a visualisation of journal entries and facilitates annotation of data. .

At the point of data entry, the rehab participant specifies which peers can view that item of data. Peers can view the web journal of participants they know and leave messages of encouragement. The spatial constraints of this paper prevent a thorough discussion of Collabohab's design and functionality, for more information please see [12].

III. The Study

The study took part in a 10–week cardiac rehabilitation (CR) program open to individuals who have recently undergone cardiac surgery or have suffered a cardiac event. Those who accept a place on the rehabilitation programme attend a preliminary session where baseline observations are made, tailored physiological and behavioural targets are determined, and a program is devised. Over the course of the 10-week program, participants are invited to attend weekly exercise classes and health/lifestyle educational sessions. At intermediate points during the rehabilitation program a rehabilitation nurse formally reviews their behavioural and physiological progress. The programme actively encourages the involvement of friends and family in an individual's rehabilitation, but at present there are no formal mechanisms through which such involvement is facilitated.

The pilot study ran for 8 weeks between 22nd October 2007 and 17th December 2007. A survey of access to technology within the programme (carried out earlier that year) indicated 45% home access to the Internet and 70% mobile phone ownership [thesis]. We hoped to recruit four participants, but due to recruitment difficulties explained in the following section, could only recruit three (one of whom had to drop out after being admitted to hospital for an unrelated condition). An overview of their background is given here.

Andy is a 71 year–old male who was enrolled on the CR program following cardiac surgery. He attributed a high adrenalin/stress lifestyle, lack of exercise and diet that was 'not as good as it should be' as possible contributing factors. He is a semi-retired media executive who lives with his wife. They have two sons and one daughter who live in various parts of the UK. Although he was comfortable using a mobile phone and basic operations using a computer, he described himself as 'not particularly technically able.'

Bob is a 50 year–old male who was attending the programme for the second time after his second heart attack in two years. He had no behavioural risk factors, but had been pharmaceutically treated for hypertension. He lives with his partner and has no children. He visits his housebound mother approximately once a fortnight, who he describes as semi-dependent on him. He works as a consultant pathologist and is comfortable/familiar with technology (describing himself as 'pretty Internet savvy').

The remainder of this paper discusses two aspects of the study that can broadly be categorised as social and technological obstacles to system adoption. Firstly, access to technology and lack of perceived need; secondly, reluctance to involve peers in rehabilitation. We acknowledge the low number of participants involved in the pilot-study. It is not our intention to making generalisable claims about the suitability of such technology for cardiac rehabilitation. Instead, what we aim to do in the following section is make explicit and reflect on the problems we encountered. Just as reporting 'good' results are worthy of discussion in the broader community, so to does reflecting on those considered 'bad'.

A. *Technological Obstacles*

Lack of access to the Internet was the single biggest barrier to recruiting pilot-study participants. Despite the findings of the earlier survey, access rates where found to be much less than 45% while recruiting for the pilot. In one of the rehabilitation classes only 3 out of 18 patients had access to the Internet. However, access did not guarantee participation. Many prospective participants explained that although they had access to the Internet and were comfortable with email or browsing the web, they were not confident enough to try anything new.

The participants of the pilot-study raised an additional challenge for researchers in this area. Both of our participants already had established self-monitoring practices, and did not necessarily see benefit in changing from pencil and paper to computer-based monitoring. The reluctance to use a technology "for technology's sake" has since been expressed by many participants in the continuing study, and will be revisited in the Section IV.

B. *Social Obstacles*

We are primarily interested in exploring the interactions between fellow rehabilitation participants and between rehabilitation participants and their friends and family. Because of this, we had initially hoped to recruit all pilot participants from the same rehabilitation group (a condition of the ethical approval was that the boundaries between rehab groups would be maintained). Unfortunately, due to the recruitment difficulties described above, we had to extend our recruitment efforts to pool from three rehabilitation groups. The participants were members of different groups and so we lost the opportunity to explore that aspect of interaction during this pilot study.

This loss was compounded when it transpired that none of our participants wanted to involve their friends and family in the study. At the point at which they made this decision the participants had not used Collabohab, but had been introduced to the basic concept. When asked why not Bob simply stated 'I didn't think that there would be much in it for them', but then continued to explain that the type of information being entered into the system 'wasn't something that I thought they should be particularly involved in.' It emerged during the interview that although he was open with his family and colleagues about his condition, the recovery process was essentially a private one. When talking about rehabilitation he stated, 'I have regarded it as my class and you know, it's me against me working out what my body can and can't do. I have found no limits to what my body can do and that is great.'. Apart from this personal view of rehabilitation and recovery, the well-documented

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tendency of friends and family to fuss over an individual after a cardiac event may well be a barrier to the invited involvement of others in rehabilitation:

My observation has generally been that folk around me want to mollycoddle me... you know, so if I was to make any kind of comment at all it is that folk are forever saying 'don't lift that', 'don't do this', 'don't do that', and I am arguing with them saying... 'no actually I can lift this... I can do this', and there is nothing stopping me going up a ladder to take the curtains down. You know, we had a fight about that last night. We are having the house decorated at the moment and you know... who is going to take the curtains down? I am perfectly able to do that now... I know what I am doing. So maybe there are a few things that I could have entered [into the web memoir]... about observations.

Andy's reasoning for not wanting his friends and family echoed that of Bob's: 'well it doesn't really affect them anyway, I mean I am the only person... basically affected and so it doesn't affect them'. A more subtle explanation of his reluctance to involve friends and family can be found in his efforts to avoid worrying his family 'unnecessarily'. On various occasions he spoke of 'playing down' the scope of his operation because worrying the family would do no good. With respect to sharing aspects of his rehabilitation with his family he said that:

I don't think that it is a question of not sharing, but I think that you have got to share the whole context or not. And you know if I have got a twinge or worry about something then I wouldn't share it unless I knew it was part of a pattern which I knew needed to be communicated to them. I don't think that it is kind to pass on a worry to someone which they may think it is bigger than it actually is.

Similarly with Bob it became apparent that, rather than Bob being the sole recipient of social support, Bob and his partner were mutually supportive of each other. As much as Bob's partner supported Bob by encouraging (and sometimes discouraging) him from doing particular activities, Bob also supported his partner during the phase of coming to terms with what had happened. Although it is only Bob who had the MI, he talks of both he and his partner taking stock of what is important in life and 'being a bit more enthusiastic about doing things now rather than later'. While Andy also spoke of the reprioritisation that occurs after a cardiac event, he did not talk about this as a shared experience with his wife and family. Indeed, it doesn't seem that his condition had been talked about much with his immediate family, as when asked how his wife dealt with his upcoming operation he responded 'fairly calmly I think', and of his children 'I don't actually know if they knew what was involved'. Just having a loving family there was enough for Andy; even though he hadn't needed them, he knew they were there if he did.

Both participants had families that were not necessarily actively involved in their rehabilitation but were nevertheless sources of anticipated support. In these cases, both participants were happy with the levels of support that they received and did not want to increase the levels of involvement: partly due to the independent ownership of the rehabilitation that they both expressed and partly out of care for the families, not wanting to worry or burden them. It could be argued that technology such as Collabohab could help rehab participants indirectly display how much they 'can' do to friends/family who tend to mollycoddle them, but a challenge would be to balance that with the desire for independence. The fact that both participants were happy with existing levels of support indicates that they are not the type of rehab participant who stands to benefit most from such systems.

IV. Discussion

The overall goal of the study is to investigate the dynamics of peer involvement in cardiac rehabilitation and to establish the potential for appropriate technological support. Collabohab was designed as a probe to reveal information disclosure practices throughout the course of the rehab program between friends and family members, fellow rehabilitation peers, and rehabilitation staff. Unfortunately, the probe itself proved to be a significant barrier to recruitment, those who were recruited didn't have the opportunity to interact with peers through it, and chose not to involve friends or family members. In this sense the probe did not serve its purpose; nothing related to the initial objectives of the study has been learnt from its use. The main findings of this study were generated by the rejection of the probe and the qualitative interviews.

Our participants were socioeconomically fortunate, highly motivated and well supported. And while it doesn't seem that they stand to benefit much from any subsequently developed system, we can learn from their situation and experiences of what it means for them to be supported through cardiac rehabilitation. Whether those not as fortunate as our participants have similar, additional, or unrelated needs is yet to be seen.

Given the outcome of the pilot study we decided to continue our investigations without the technology probe. This way, we have been able to explore the original aims of the study alongside the questions raised during the pilot with a broader demographic of rehabilitation participants. Here we briefly discuss some of the pragmatics of our experience in the hope that the pervasive health community can learn from our 'mistakes'.

Despite the ambiguity surrounding the practicalities of social support it is widely accepted as a resource for behavioural change. HCI practitioners have been exploring social support within generic health-related behavioural change technologies [4,5,6,7]. When applying the same lightweight social networking approach to a cardiac rehabilitation domain we have found that our assumptions did not stand.

Our approach embodied a naïve representation of social support, one that could be observed and measured through computer mediated interactions. Our intention was to explore the concept of social support through the probe, but the disparity between our initial understanding and the existing practices of the population was sufficient to render our approach inadequate.

The fact that the participants had made their decision not to include peers before they had used Collabohab means that it was not the design *per se* that led to this decision, we cannot

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rule out the possibility that it was the concept behind the design. Therefore, it could be argued that a different system, which was of more value to the participants, would have engendered the inclusion of peers. Although a technology probe is intended to be a tool through which research is carried out rather than a potential intervention, when the study involves populations other than 'early adopters' [13] even a probe must be of value to them, as perceived by the population itself.

Participatory design is one approach to increase the input of the user population. However, we suggest our experiences highlight the need for initial investigations to start with an even less technocentric approach. The lack of benefit from further self-monitoring as perceived by the pilot-study participants supports previous findings that emphasise the importance of perceived medical usefulness [14] and also supports the need for value-centred HCI [15]. The lack of perceived benefit of self-monitoring has been a recurrent theme in the main study, one participant rather tellingly commenting:

I mean if somebody was to say to me would I take a pedometer to check things out for the sake of a study or something like that then, yeah by all means to run for a month or something like that but... it is not something I would use necessarily.

By first aiming to understand what is of value to the target population, we can shape future innovations that are subsequently more likely to resonate with that population.

That said, it may well be that the reluctance to involve peers is a true reflection of the mindset of the participants and that peer-based applications are unsuitable for cardiac rehabilitation; these issues are being explored in the ongoing study. When considering how pervasive health technology can be designed in acknowledgement of the values that emerged from this study: *independence* and *anticipated social support*, our preliminary suggestions are to focus primarily on the individual, and rather than promote active involvement, mediate anticipated social support:

- Pervasive monitoring could be utilised to communicate progress to peers in an effort to alleviate the problem of 'mollycoddling'
- Monitored data need not be broadcast to peers, but be available to the individual to send or show to their peer when such a conflict arises
- For those with strong support networks this computer mediated anticipated support may take the form of "virtual post-it notes" that their peers can leave for them
- For those with weak support networks, portals to local community resources as well as relevant online communities should be provided

V. Broader Implications

From a small pilot-study such as this it is impossible to make sweeping statements or claims of generality. The conflicting findings from the pre-study survey and the pilot-study with regards to Internet access suggest we may have been 'luckier' if we had recruited from a different cohort of rehabilitation participants. However, the changing profile of the rehabilitation programme's demographic is central to the wider problem of developing pervasive health technologies.

We do not suggest that any technology developed for this population will be rejected; throughout the UK cardiac rehabilitation programs are developing online programmes for those who cannot, or do not want to, attend rehabilitation in-person. Of course, the argument that such interventions will be much more suited for the next, more tech-savvy, generation may apply. However, that does not address the problem of exploring the area and potential for technological support in the immediate future. For that, we suggest embarking on qualitative explorations of the needs and values of underserved populations that can then inspire and shape new genres of pervasive health technology.

References

[1] Franks, M.M., Stephens, M.A.P., Rook, K.S., Franklin, B.A., Keteyian, S.J., and Artinian, N.T.: 'Spouses' provision of health-related support and control to patients participating in cardiac rehabilitation.' Journal of Family Psychology., 2006. 20(2): p. 311-318.

[2] Chronister, J., A., Johnson, E., K., and Berven, N., L: 'Measuring social support in rehabilitation', Disability and Rehabilitation, 2006, 28, (2), pp. 75-84

[3] Consolvo, S., Everitt, K., Smith, I., and Landay, J.: 'Design Requirements for Technologies that Encourage Physical Activity'. Proc. CHI, Montreal (2006)

[4] Gasser, R., Brodbeck, D., Degan, M., Luthiger, J., Wyss, R., and Reichlin, S.: 'Persuasiveness of a Mobile Lifestyle Coaching Application using Social Facilitation'. Proc. Persuasive (2006)

[5] Lin, J., J., Mamykina, L., Lindter, S., Delajoux, G., and Strub, H., B.: 'Fish'n'Steps: Encouraging Physical Activity with an Interactive Computer Game'. Proc. Ubicomp, Portland (2006)

[6] Maitland, J., Sherwood, S., Barkhuus, L., Anderson, I., Hall, M., Brown, B., Chalmers, M., and Muller, H.: 'Increasing the Awareness of Daily Activity Levels with Pervasive Computing'. Proc. Pervasive Health, Innsbruck (2006)

[7] Maitland, J., and Chalmers, M.: 'Finding a balance: social support v. privacy during weight-management'. Proc. CHI '08 extended abstracts on Human factors in computing systems, Florence, Italy (2008)

[8] Maitland, J., Siek, K. and Chalmers, M.: 'Persuasion not required: imporoving our understanding of the sociotechnical context of dietary behavioural change'. Proc Pervasive Health, London, UK (2009)

[9] Hutchinson, H., Mackay, W., Westerlund, B.. et al.: 'Technology Probes: Inspiring Design for and with Families'. Proc. CHI (2003)

[10] Mamykina, L., Mynatt, E., D., and Kaufman, D., R..: 'Investigating Health Management Practices of Individuals with Diabetes'. Proc. CHI, Montreal (2006)

[11] Dawe, M.: 'Desperately seeking simplicity: how young adults with cognitive disabilities and their families adopt assistive technologies'. Proc CHI, Montreal (2006)

[12] Maitland, J. 'From perusasion to negotiation in health promoting technology'. Unpublished Doctoral Thesis (in submission)

[13] Moore, G. A. Crossing the Chasm: Marketing and Selling Technology Products to Mainstream Customers. 2001. Capstone, UK.

[14] Scheermesser, M., Kosow, H., Rashid, A., and Holtmann, C.: 'User Acceptance of Pervasive Computing in Healthcare: Main Findings of Two Case Studies'. Proc. Pervasive Health (2008)

[15] Cockton, G.: 'Value-Centred HCI'. Proc NordiCHI (2004)

Digital Object Identifier: 10.4108/ICST.PERVASIVEHEALTH2009.6010
http://dx.doi.org/10.4108/ICST.PERVASIVEHEALTH2009.6010