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Getting Better Together? Opportunities and Limitations for Technology-Facilitated Social Support in Cardiac Rehabilitation

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Abstract. Social support has long been positively correlated with cardiac outcomes. However, sources of tension surrounding peer-involvement in the period following acute cardiac events are well documented. Informed by a previous study of patient perspectives of peer-involvement in cardiac rehabilitation, this paper draws from the cardiac and computing literature to provide actionable insights into how technology could be designed to promote appropriate peer-involvement and the challenges that may be faced when designing technologies to support the unsupported.

Keywords. Social support, cardiac rehabilitation, computer-mediated communication.

Introduction

Social support is positively correlated with cardiac outcomes including recovery from myocardial infarction (MI) [1], participation in cardiac rehabilitation programs [2], and health-related behavioral change [3]. It can be so strongly linked that the lack of a social support network (social isolation) has been deemed to be a risk factor for both the development of coronary heart disease (CHD) and prognosis of established CHD [4,5] equivalent to “classic” risk factors, such as high cholesterol and smoking [6]. While there are social support structures (both health professional- and peer-based) in traditional cardiac rehabilitation programs in hospital and community settings, the primary focus remains on physiological recovery through cardiovascular exercise, rather than psychosocial interventions. However, patient-based support groups appear to be promising venues for non-traditional support provision [5,7].

Reflecting the focus of traditional cardiac rehabilitation, technological innovations and research in this area are grouped around web-based delivery of rehabilitation programs and physiological monitoring. Here, we are concerned with examining the potential role for technology in promoting social support for cardiac rehabilitation participants. As such, informed by the cardiac and computing literature, this paper draws on the insights gained into patients’ perspectives of peer-involvement during a qualitative study of cardiac rehabilitation participants [8,9] to identify avenues of opportunity and constraint for technological interventions in this area. Before that, we

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commence with a brief overview of the study, the methodological and analytical approach employed, and the findings. For further details, we refer the reader to [9].

1. Method

Participants were recruited at the end of a ten-week cardiac rehabilitation program. Nineteen cardiac rehabilitation participants were recruited for the study. The majority of participants were male (n=14). Of the five female participants, three were widowed, one was married and the other was living with her common-law husband. All but one of the male participants was married or living with their common-law wife, the other lived alone but had a long-term partner. One of the married male participants also lived alone. Apart from the gender bias, the participants represented a broad demographic: participants were aged between 43 and 78 (average age= 63.1; s.d. = 10.8) and occupations (and pre-retirement occupations) spanned the manual-professional continuum, including janitor, domestic, policeman, nurse, engineer and laborer.

The interviews were performed at the participants' homes, and were structured around topics such as their cardiac event and rehabilitation, health-related behaviours and change, peer-involvement, and technology use. Each interview lasted between 45-90 minutes. All interviews were audio recorded and transcribed. Employing inductive analytic methods advocated by Lofland et al. [10], transcripts were initially subjected to open coding, whereby each sentence was analyzed in a process of sensitisation. The emergent codes were then subject to more focused coding, whereby similar codes were grouped together to form categories of phenomena. Similarities and differences were compared and contrasted, and the data was repeatedly revisited. Themes emerged that were then used to structure the data presented in [8,9], the latter of which we draw from here.

2. Results

Although experienced to a degree by members of an individual's family, a heart attack happens to the individual and it is the individual who needs to physically recover. We observed two broad categories of social network members found in this study: the inner core group and others. Inner core members were typically immediate family and provided the bulk of support. The distinction within an individual's social network between their inner group and others resonates with the notion of support cliques and sympathy groups discussed by Dunbar et al. [11]. Peer-involvement typically took the form of practical assistance, behavioral guidance or emotional support. The degree to which family members were involved in an individual's recovery and rehabilitation depended on many things including perceived need for support, desire for independence and social proximity (geographic and emotional). In particular, the findings highlighted two aspects of peer-involvement, namely tension between an individual and their peers, and the challenges of providing social support to those who have none. Here we reflect on the study's findings and consider the implications for research and design in the area of technology to promote social support within cardiac rehabilitation.

We found that following the event, both the individual and his/her family members undergo a period of uncertainty regarding what is physically safe for the individual to

do and what will be possible for the future. In the cardiac literature, this is referred to as the period of adjustment. The supervision and encouragement of the rehabilitation staff, combined with the physical progress that the individuals can see and feel over the course of the rehabilitation program, serve to increase the individual's confidence with respect to what is physically possible. Family members, however, do not see what the individuals do during the exercise classes and so have to gain confidence by proxy: through verbal reassurance from the individual. Much of the cardiac literature calls for a greater involvement of spouses in the cardiac rehabilitation program [12-15]. However, for participants such as those who viewed the rehabilitation as their private battle, the prospect of further involving peers in the process is likely to be frowned upon.

Only three participants voiced dissatisfaction with the level of support that they had received from their families. Not wanting to be a burden, none of the participants had discussed these issues with their family. In each case, the issues did not seem to be exclusive to the cardiac condition but rather to stem from the nature of the existing relationships.

3. Discussion

Instead of proposing ways in which technology can assist peers in becoming more involved in an individual's rehabilitation, as we had first imagined, we suggest that technology be designed in such a way so as to build confidence by proxy. Here we propose and discuss three design strategies to promote peer confidence by proxy (listed in Table 1).

Pervasive monitoring technologies could be utilized during rehabilitation classes to convey objective measures of progress to their peers, in an effort to build peers' confidence, and potentially alleviate unnecessary mollycoddling. Rather than automatically broadcasting progress to the inner core we would suggest that the individual should control information disclosure, as is currently practiced. Although the retention of information was cited as a source of frustration for peers elsewhere [15], controlled and selective disclosure is intrinsic to the maintenance of privacy. It is also especially important when considering the importance of the act of enquiry itself. Alongside interactions elsewhere viewed as controlling and potentially harmful, such as verbal instructions and emotional blackmail [3], enquiries were considered to be a caring gesture; a meaningful expression of concern. If information were automatically broadcast about a person to immediate family, this would reduce the need for him or her to ask how the individual is feeling that day. In other medical situations, such as when a family member is in intensive care the automatic broadcasting of updates may ease the burden of responding to enquiries [16], but here we suggest that it may reduce interactions that contribute to an individual's sense of support. Furthermore, the automatic broadcasting of information may be seen as demanding attention from the family members, something actively avoided by many participants.

Table 1. Designing to promote peer confidence by proxy.

Utilise pervasive monitoring to convey objective measures of progress to their peers
The individual should control information disclosure
Deliver peer-specific rehabilitation programs that run separately to the individual's program

As well as the difficulty in finding a balance between acceptable dependency and being a burden, finding a balance between peer involvement and interference is another well-documented source of tension [3,15,17,20]. In contrast to previous work, for the most part we found that individuals were tolerant and even appreciative of potentially intrusive involvement of their family because of an implicit understanding of the underlying motivation behind the family members' actions: caring concern. However, our study was concerned with establishing the response of the individual to peer involvement and we did not measure behavioural outcomes. Given the findings in the cardiac literature that suggest spousal control contributes to negative health outcomes, perhaps technology could contribute to reducing this area of tension. In addition to the earlier suggestion of a system to provide confidence by proxy, technology could also be used to deliver peer-specific rehabilitation programs that run separately to the individual's program. In this way peers could benefit from a cardiac rehabilitation program while the individual retains ownership of their program.

Similarly, participants appreciated offers of help and assistance even if they did not need to or want to call on those offers. The evident importance of anticipated support supports findings from gerontology that suggests anticipated support is more valuable to elders than practical support [19]. It is easy to envisage a computer-mediated anticipated support system by which friends and relatives leave virtual post-it notes containing good wishes and offers of assistance, a virtual get well card. However, particularly in view of this population's attitude towards technology (an overall reluctance to use technology "for technology's sake" [8]), the question that must be asked is what value would such a system add? The vast majority of our participants were happy with their existing levels of support, which, when from people who weren't co-located, came in the form of personal visits, phone calls and emails.

Here we find the crux of the problem when considering the design of peer-based technologies for cardiac rehabilitation. The people who feel that they are well supported do not necessarily need technology to mediate or augment the support processes and structures that they have in place, and clinically there is little to be gained from further enhancing moderate or strong support [1]. For those with weak support structures, it is naive to think that technology can improve what is essentially the nature of their relationships with their peers. Peer-based systems that forge new social ties such as forums may offer some purchase on this problem, but there are limitations in addition to the relative technical and literate expertise required to access and participate in traditional forums. Firstly, when considering the experiences of this study's participants, much of the value of the offers of support and good wishes was in the underlying emotions that they conveyed which are unlikely to be replicated in newly established social ties. One strategy to overcome the limitations of online support would be for portals to point to local community resources as well as relevant online communities.

Lastly, and perhaps more importantly, those who are not used to seeking support may not feel able or willing to proactively search for it. Note that two of the participants with the weakest support structures were the only ones not to engage in discussions with the other rehabilitation participants in their class. Technology can play a limited role in that anonymous and asynchronous communication seems like possible technical strategies to promote the establishment of social ties. However, it is likely that in cases where individuals are unaccustomed to seeking or receiving social support, such skills may need to be developed independently of any technological intervention. Indeed, Arthur [1] similarly suggests: "A pre-requisite for benefit from peer support

groups is the availability, and prior use, of social support networks in other aspects of life.” Before technologists can realistically contribute to increasing the provision of support to those who currently have none, more research is required to understand the nature of support seeking practices of individuals with poor support structures.

4. Conclusion

In highlighting and discussing the problems of peer tension and supporting the unsupported, the original study deconstructed the somewhat abstract notion of social support. The further analysis and discussion presented in this paper now provides actionable insights into how technology could contribute and the challenges that may be faced.

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