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Communities of Support

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Abstract

Support groups play an essential role in the ongoing care of health sufferers, and have proved their value over the years. However, support groups have also proved to be somewhat unstable, often relying on the involvement of one particular person. Similarly, traditional face-to-face have necessarily been geographically constrained and meet only occasionally, at specific times and in specific places. All of these factors restrict the reach of these groups.

The Internet has the power to alleviate many of these restrictions; for instance members can be online at any time, from (more or less) anywhere. Online communities bring their own set of problems. For instance, there is no guarantee that all members will be in the same time zone, so discussions can become very disjointed. Also, there is no way to identify members' cultural origins, allowing the possibility for members to accidentally give or take offence.

This paper introduces the concept of a "Community of Support" (COS). In many ways a COS is very similar to a "Community of Practice" (COP). This paper uses Actor Network Theory as a lens to compare face-to-face COS with their virtual, online counterparts. The roles of the focal actor and non-human actors (actants) are examined, and particular attention is paid to the final "moment of translation", that of "mobilization", and how it influences

the activity and sustainability of the community. The conclusion drawn is that COS are indeed viable, stable actor networks, but that more work needs to be done in the area of Internet-based COS.

Keywords: health, support, group, virtual, community

1 Introduction

“Hello. My name is Jay, and I’m bipolar”.

Thus starts a typical meeting of one of the Cape Town Bipolar Support Group meetings that my wife and I have been running for this past 12 years.

Many people, for a variety of reasons, cannot or will not attend face-to-face support group meetings. The Internet is now being used to extend support groups to accommodate such people, but little is known about the behaviour patterns of these groups.

The intention of this paper is to introduce the concept of “communities of support”. Based largely on Lave and Wenger’s (1991) concept of communities of practice, this paper will show that communities of support need to be considered as a new category of community, having as they do different goals, objectives and constraints. Both face-to-face and virtual communities are discussed. Actor-network theory is applied to the community of support concept in order to better help define and understand the term, and to try to predict factors they may help or inhibit the success of such communities.

2 Background and context

I was diagnosed with bipolar disorder more than 20 years ago. For the first 10 years of my bipolar life I lived with and fought the disorder almost entirely alone, having lost my wife (and children) during my first major manic episode. I was diagnosed whilst working for a university, and was lucky enough to be taken under the wing of the then Head of Department of Psychology. Through her I experienced my first taste of psychotherapy and learned the value and necessity of educating myself about this illness, and of having “support”. Some 12 years after the diagnosis, I moved to Cape Town, I eventually met my (now) wife, Michelle, who became my second “supporter”. We heard of a bipolar support group being started in Cape Town, and attended the second meeting. It became clear to me that in many ways I was “ahead” of the other group members by virtue of my time spent in therapy and through my personal research into the illness. When the original group convener decided to pull out of the group, Michelle and I immediately and gladly took over the reins. We could thus offer two perspectives to group sessions, those of supporter and supportee (see later).

The efficacy of support groups is well documented. For instance Kurtz (as cited in Kyrouz, Humphreys & Loomis, 2002) states that more than 80% of a manic depressive and depression group members reported coping better with their illness since joining a group, and the re-hospitalisation rate dropped from 82% to 33%. Edmunson *et al.*, (as cited in Kyrouz *et al.*, 2002) report that such participants in another group spent less than one third as much time in hospital as non-participants, and that more than twice as many of them could function with no contact with the mental health system. Rodgers and Chen (2005) report that, in an online group dealing with breast cancer, the number of participants feeling optimistic about their illness almost tripled, with almost half the group reporting an increased ability to cope with their illness. Huntingdon, *et al.*, (2004) also report a general positive outcome from online support group users, with a greater likelihood that patients will engage with the medical profession.

3 Introducing the term “supportee”

There seems to be no good single word for someone who receives support. “Patient” implies that someone is under direct medical care, which may not be the case. “Sufferer” offends some “patients” who prefer to describe themselves as “living with” a particular illness rather than “suffering from” that illness. The terms “client” and “consumer” are also used occasionally, but there is no sense of caring implied in these words, only a sense of purchasing. Then again, none of these words apply to a non-medical scenario of receiving support.

The closest applicable word in dictionaries and thesauri seems to be “supported”, but this implies a passive role in the process, not the active role that such people play when deliberately seeking help from some sort of help group or another. It is therefore proposed that the word “supportee” – one who is supported – be adopted, and this paper will use this word in this way. This is linguistically supportable; the suffix is derived from the French passive participle ‘é’ or ‘ée’ and is interpreted as someone (or rarely something) that receives or benefits from a specified action. Other examples are interviewee, escapee, absentee and refugee, all of which convey the same sentiment of active participation.

4 The use of the Internet for health purposes

In order to understand the importance of online support groups, it is useful to examine the use of the Internet for health related purposes. There are many sources of Internet usage statistics available on the Internet, and choosing one is a somewhat arbitrary decision. The Pew Internet and American Life Project

(<http://www.pewinternet.org>) has a significant number of references to health usage to warrant its use for this article, and is widely cited.

According to Pew, 80% of all Internet users look for health and/or medical information, which amounts to more than 250 million people (http://www.pewinternet.org/trends/Internet_Activities_2.15.08.htm). According to Nicholas, Huntington, Gunter, Russell and Withey (2003) “[M]ore than 40% of all Internet users... have sought health related information, making it second only to pornography in popularity”! This increase is attributed largely to the rapid uptake of broadband technologies, especially in first world countries.

Pew also finds that 23% of all Internet users search for depression and mental health information, indicating both the extent of the mental health problem and the utility of the Internet for possible sources of assistance (http://www.pewinternet.org/pdfs/PIP_Healthtopics_May05.pdf). This is in line with the Prince et al. (2007) observation that “Of all the non-communicable diseases, neuropsychiatric conditions contribute the most to overall burden, more than either cardiovascular disease or cancer.”

There has then quite logically been a rise in the number of online health sites in recent years, many of which purport to be “online support” sites for very specific illnesses. For instance Marziali, Damianakis & Donahue (2006) describe an online support group for family caregivers of people with neurodegenerative diseases that specifically set out to emulate the experiences of a face-to-face group. (This follows the recent “social networking” boom, driven largely by Facebook, Myspace, Youtube *et al.*)

5 Face-to-face support groups and their limitations

Although, as stated, support groups have manifest benefits, a serious limitation with them is their restricted geographical reach (Lin, 2007). For instance, the Cape Town bipolar support group originally met in a church hall in a central location in Cape Town. For a variety of reasons it was decided to move the meetings to the premises of a private psychiatric clinic. This had the added benefit of “legitimizing” our group through its association with a formal health-care institution, even though the group has never had formal ties with that institution. The major trade-off was that this new venue was not quite so central. A second factor mentioned by Lin (*ibid*) is that of “lurkers”. These are people who, in online communities, read but don’t participate. Face-to-face groups have their share of “lurkers” (assuming the style of meeting permits it), but at least the lurkers can be seen and are known to be there. Someone who only participates by reading an online site late at night may never

be noticed by the group at large, and this raises issues of trust and anonymity with the resulting potential disinclination for members to participate.

On two or three occasions various people tried to start other bipolar support groups in Cape Town, either in different areas or with different agendas, but they have sooner or later failed. It appeared that the original group succeeded because it managed to attract and maintain a certain (but undefined) minimum attendance level. This has been confirmed by Preece, (2000) as a requirement for online groups too. This minimum attendance level gives people the safety of anonymity should they so choose, but it also gives them the opportunity to speak and participate as and when they so desired. If a large number of attendees arrive, the group is split and run in parallel sessions – but the concern has always been that too few attendees would be the death knell for the group, as attendees would feel that the group was a “failure”, that bipolar disorder was in some way not important, and thus choose to not attend subsequent meetings. Group meetings are advertised in local community newspapers, on information “flyers” distributed to hospitals, clinics and doctors’ waiting rooms, and interviews by local radio stations are arranged, all with the intent of advertising the group and maintaining the attendance figures.

Eventually a second clinic contacted us and asked if we would be prepared to start a second group at their premises. Although Cape Town is not large, transport across the city can be problematic, and since the new venue would serve a perceived new geographical area (the “northern” suburbs and opposed to our current “southern” suburbs venue) we agreed to participate. It was clear to us that the clinic would start a group anyway and we wanted to try to ensure that it would be successful by infusing it with our proven formula. (At least that was what we told ourselves, but on reflection our motives probably included a desire to “own” bipolar support in Cape Town. We had by this time invested so much of ourselves into bipolar support, and our names were so closely linked with it, that we were worried about the possibility of people becoming reliant on a group and of that group failing, thus leaving people who had just started getting used to having support with no effective local support structure.)

The original group leader also started the South African Bipolar Support Alliance website, and through this website many people dotted all over South Africa are supported using email. Support groups have been successfully started in other cities around South Africa, but surprisingly few of them persisted, even in large cities, and none exist in smaller towns to our knowledge.

6 Communities of Practice

Lave and Wenger (1991) originally coined the term community of practice (COP). It can be simply defined as “self-organising groups of people with an interest in a particular practice” (O'Hara, Alani & Shadbolt, 2002). COP are most often associated with peer group knowledge sharing within a specific work domain, either within an organisation or across organisational boundaries. The essential principle however is that of *peers* communicating, sharing and learning. Wenger (2004) talks of the “horizontalization of learning”, or peer learning, as compared to vertical learning, the traditional teacher/learner (producer/consumer) situation of regular classroom style teaching. COP are very much oriented to horizontal learning.

Lave and Wenger (1991) introduced the concept of triadic relationships in COP between “apprentices”, “young masters” and “masters”. An apprentice is considered to be a new entrant to the field of practice, a young master to be someone who has mastered the skills of the practice but has not yet developed an insight into the practice, and a master to be someone who, through study, practice and experience has become a contributor of “new practice”.

These three levels can be seen operating in our support groups, and can be expected to be found in all support groups. The apprentices are those people newly diagnosed with an illness such as bipolar disorder, their existing supporters (typically family members or close friends), and those who suddenly, unexpectedly, find themselves participating in the practice of support through other means, such as in workplace or as new acquaintances. Young masters are those supporters and supportees who have lived with the illness for long enough to understand the mood swings and their consequences, who understand the importance of long term medical treatment, and who in general are in more or less control of their own illness. The masters are those who have had sufficient exposure to the disorder, either as health professionals or long-term support group members, to be able offer both subjective and objective help and support, proactively and reactively. This “mastership” could be gained through active involvement with a support group, or through professional study as in the case of qualified psychiatric practitioners and counsellors.

Two other levels are apparent in our support groups, however. Firstly there is what can be best described as “innocent bystanders”. These are people who originally had no direct involvement in the illness, but now find themselves in the role of inadvertent supporters through work, social or some other chance circumstance. Such people cannot really be described as apprentices, as the term suggests that there is both a desire to become a

supporter and desire to ultimately progress to mastership, which may not be the case. Secondly, and perhaps most strangely, there are occasional “wannabes” – people who want to be involved in a support group for their own peculiar agenda, and may even pretend to have the illness in order to gain entry and acceptance. Such people can be considered as “dangerous”, in that their “wannabe” status is obviously undeclared, and thus their contributions to a group are considered to be legitimate, whereas their advice and suggestions could actually be quite destructive. This deliberate misrepresentation was also identified by Feldman (as cited in Burnett & Buerkle, 2004).

The principle of deliberate peer learning is not the only reason for attending a support group. Not everyone comes to learn. Some come purely for the social dynamic of the group, to be with, both emotionally and physically, people with the same or similar set of problems. Others come because they have no other support. Still others use the group sessions as their monthly psychotherapy session. None of these participants truly fall into the ambit of COP participants.

Despite the universal acceptance of the concept of “community of practice”, other specializations of COP have been defined. For instance, Coakes and Smith (2007) define a community of innovation (COInv) as being a type of COP formed to promote organisational innovation. They specifically note that a “zone of safety” is required in such a community, and indeed propose the safety factor as the main differentiator between COInv and COP. In the context of a health support group, several practices can be seen to exist; those of the medical professional (how to treat the illness), the supporter (how to live with the illness, from the outside) and the supportee (how to live with the illness, from the inside). These three aspects are necessarily somewhat different from each other, requiring, strictly speaking, three separate COP, but in this context need to co-reside.

Lave and Wenger’s (1991) original concept of COP seemed only to be concerned with relatively “static” knowledge. Support groups generate a lot of “dynamic” knowledge in terms of experiential, day-to-day knowledge, which is yet another departure from the original COP idea. A support group can then be seen to be a specialized community in its own right. Thus the term “community of support” is now introduced, to differentiate between COP and support group communities.

7 Community of Support

7.1 Community of Support defined

A Community of Support (COS) can be thought of as a group of people who cooperate to help themselves and others to surmount a common problem. This does not imply that COS must be large, organized, public groups. A supportee's immediate family and friends who are involved in the process of support constitute a COS. However, the intent of the term is to describe formally constituted, public structures such as support groups, self-help groups and mutual-help groups.

Bruckman (as cited in Preece & Maloney-Krichmar, 2005) feels that there is little point in trying to narrowly define what is or is not a community (particularly online communities). However, a definition will go a long way towards specifying the software requirements for applications to support such communities, in particular the "domain requirements" (Somerville, 2007). Domain requirements are generic requirements that apply to a particular system or type of system, as opposed to specific user requirements. Clearly, most COS will have similar issues in their design and implementation. Somerville (2007) also talks about "emergent properties" of systems - properties that only become apparent after implementation. Examples of these might be the declining use of discussion forums after implementing a chat room, or the need for multiple chat rooms to accommodate multiple languages.

COS predominately operate in the health arena (because of the sympathetic and empathetic aspects), and thus we find support groups for people diagnosed with a host of both physical and mental illnesses, as well as support groups for care-givers of the above (Radin, 2005).

The terms "support group", "mutual aid group" and "self-help group" all relate to COS. The first commonly accepted success story for a self-help group was Alcoholics Anonymous, which started in 1935. The medical profession was, at that time, largely unsuccessful in treating alcoholism (Oka & Borkman, 2000). They also report that World War 2 interrupted the widespread development of self-help groups, and it was only in the 1960s and 1970s that groups started to emerge for other health problems, particularly in Japan and Germany. The boom in global communications experienced in the 1980s and the Internet in the 1990s led to global acceptance of such groups, culminating in online support groups.

Until the upsurge of widespread digital communication, notably the Internet, COS existed only in face-to-face (F2F) format. In this scenario, people gather at a prescribed time at a nominated location to participate in their COS. This, of course, means there are administrative overheads in arranging dates, times, venues, etc. Time and location fixed meetings inevitably prohibit some people from attending meetings, due to other commitments. Other problems also arise during meetings, such as the disruption caused by late arrivals, or by unruly attendees. Moderation of a group session can be very difficult, and whereas one may be tempted to think that a support group would be self-moderating, this has not been found to be the case. A further problem with F2F meetings is that either the group leader needs to be present, or someone needs to fulfil that role in order to ensure that the meeting is conducted to the normal practice. In addition, some participants may suffer stress through attending the meeting, the stress being caused either by embarrassment, by being overwhelmed by the meeting, by not feeling worthy of speaking, or several other reasons. (Galinsky & Schopler as cited in Mohr, 2004).

F2F meetings do however have a number of positive features. Potential attendees know that there will indeed be people there to provide help (unless, of course, the meeting is totally unsupported), unlike virtual, Internet-based COS where, amongst other things, time zones must be taken into consideration. A second feature of F2F meetings is that non-verbal communication (“body language”) is present, enhancing the overall communication, and hence learning opportunities. Thirdly, there is typically a fair amount of off-topic conversation and interpersonal networking, which again enhances the learning experience.

7.2 Virtual Communities of Support (VCOS)

In order to cater for all those people who either cannot or will not attend a face-to-face group meeting, I started an online bipolar support group in April 2008. One of the primary goals for this was to create a pseudo-physical “place” where bipolar supportees and their supporters could “meet” and “talk”, thus creating the (somewhat obvious) metaphor of “a virtual community of support is a face-to-face support group”, and participants quickly started using phrases that embodied that metaphor such as “will you be in tomorrow”, “hold on, someone else wants to chat”, etc.

Virtual, Internet-based communities have been in existence for many years, dating back to the original “usenet” groups and email “list-servers”. Many such communities have existed for many years, and continue to exist, with apprentices, young masters and masters, as described above, all being present from time to time.

VCOS align well with Porter’s (2004) typology of virtual communities, as shown in Table 1.

Table 1 - Porter's (2004) typology of virtual communities applied to VCOS

Purpose:	Health information and patient support.
Place:	Online.
Platform:	Hybrid: Synchronous in terms of chat room and possible future voice and video conferencing. Asynchronous in terms of blogs, discussion groups etc.
Population Interaction Structure	Indeterminate: many members, but relatively few active at any given time.
Profit Model	Strictly non-revenue seeking.

This turns out to be a very concise and convenient way of summing up our online support group, and lends credibility to Porter's model.

VCOS have much in common with their F2F equivalent, especially in terms of the "...stable core of participants whose candid messages, loving encouragement and work on behalf of the website make it clear that a productive social network has been formed." (Radin, 2005). This has been noticed, and even relied upon, in the face-to-face groups, and it is already emerging in the experimental VCOS. In Wenger's terms, we are progressing members through the "apprentice, young master, master" cycle. The real challenge is to keep the masters contributing. There is a strong tendency for people who are now "well" to leave the group, thus depriving the group of their "master" expertise. This is another point of departure of a COS from a COP. Once someone is a master (i.e. "well") they generally want to rid themselves of reminders of the illness, and support groups are very much that.

VCOS also solve some of the administrative problems mentioned earlier, as well as providing access to a wider base of information and experience and a more diverse range of participants. It has been reported that the anonymity of the Internet can be of great help in this regard, as some people are more likely to "open up" if their identity can be hidden (Leimeister & Krcmar, 2005). Experience with the current bipolar VCOS is somewhat conflicting; some people are known to have lied about their identity, whereas others are asking for people to post true photos of themselves online rather than use the default or some uploaded graphic to represent themselves as

they would feel more comfortable if they could “see” who they are corresponding with. However, VCOS have their own set of problems. Due to the possible diverse time zone locations of participants, and because there may well be no organized meeting time, it is often the case that there are no other people on-line, especially if the community is chanced upon in the process of casual browsing. This is not a problem if timeliness of interaction is not an issue, since many modern technologies implement stored-message content, for example “blogs”, “wikis”, discussion forums and email, listed by Leimeister and Krcmar (2005) as the most used and most important technologies implemented in online health communities. Indeed, Radin (2005) finds that this stored message approach is one of the things that most on-line support forums have in common.

A major problem is that there is (still) no way of positively identifying other participants in a virtual community. Even though usernames and passwords may strongly suggest that this person is the same person who logged in under that identity previously, it can no longer be automatically assumed to be the case, given the incidence of identity theft on the Internet. Even worse, even if the person is the same person as previously logged in, there is still no simple positive way of identifying that a person is who they claim to be over the Internet. The use of aliases is commonplace, and indeed many websites implement avatars specifically to help participants hide their real identities and characters. Thus it is impossible to determine a participant’s socio-economic or cultural status, making meaningful interaction very difficult. Worse, there is no way of ascertaining that the participant is even a “legitimate” member of the community, with possible dire consequences in critical, life-threatening circumstances such as suicide counselling. There will undoubtedly be times when there is no group leader on line (unless this function is delegated to various people in different time zones). The group leader is often the “oracle” of a community, acting as the central repository of group knowledge and thus answering many of the questions posed to the community. The group leader is often also the “moderator” of the group, ensuring that conversations are kept civil and on topic. In the absence of group leader anarchy can, and has, prevailed.

At the end of the F2F group meetings eats and drinks are made available to encourage people to stay behind and chat. There are several benefits in doing this. Some people are too shy to talk to a whole group of people (especially if they are new), but will talk to individuals or smaller groups. Sometimes someone will bring up a point in the public meeting that another person doesn’t think warrants being discussed in the group at large, but wants to learn more about from that speaker. But in general, we encourage people to network, to swap names and phone numbers, and to start supporting each other outside of the support group meeting context. Creating this “network of support” led directly to the idea of analysing a COS using Actor Network Theory (ANT).

7.3 COS and VCOS in a developing country

Much of the aid that goes into the health sector for developing countries predictably, and rightly, goes to the chronic illnesses from which the great majority of people suffer, such as HIV/AIDS and TB. For example, a table of “quick wins in the health sector” taken from the Lancet’s “Millennium Project” shows the following:

“• The training of large numbers of village workers in health, farming, and infrastructure (in 1-year programmes) to ensure basic expertise and services in rural communities

- Distribution of free, long-lasting, insecticide-treated bednets to all children in malaria-endemic zones to decisively cut the burden of malaria

- Elimination of user fees for basic health services in all developing countries, financed by increased domestic and donor resources for health

- Expansion of access to sexual and reproductive health, including family planning and contraceptive information and services, by closing existing funding gaps on contraceptive supplies, family planning, and logistics

- Expansion of the use of proven effective drug combinations for AIDS, tuberculosis, and malaria, especially in places where infrastructure already exists but finance is lacking” (Sachs & McArthur, 2005).

Communities of support, both face-to-face and virtual could be developed to address several of these areas. Regular COS would be restricted to a geographical location, but would still serve as a forum where aid workers and experts in the field (including community members) could interact with the rest of the community. VCOS, where the technology allows, can be used to address problems not just across local communities, but across communities world-wide, thus facilitating self-help on a global scale. This may be particularly productive for providing aid for non-mainstream illnesses (i.e. those not mentioned in the above list).

Given that much of a VCOS can be implemented for free (so far as the host services are concerned) using existing Web 2.0 technologies, this would prove to be an extremely cost-effective way of addressing some of the needs of much of the population. As shown below, there are some prerequisites that need to be in place to help the chances of success, chiefly that of a committed, involved “leader” (focal actor), and of the buy-in of a community. A limiting factor will always be the lack of opportunity for severely technologically inhibited

communities to participate, but COS and VCOS are not seen as a panacea, merely another method by which to provide aid.

8 Actor Network Theory

Several researchers have developed models by which virtual communities can be analysed. For instance Hersberger, Murray and Rioux (2007) propose a conceptual framework for examining virtual communities based on information exchange within those communities. De Souza and Preece (2004) have developed a model intended to help community “designers” better meet the proposed community need. Given that many people come to depend on their COS, that in some circumstances a successful COS can be the difference between life and death, it is essential that the elements contributing to COS success and failure be understood. Garber (2004) observes that “Too often the assumption is made that simply by putting online technology into place for people to use, we have ‘built’ a virtual learning community.”

ANT is a method of investigating what happens when social and technical issues meet. Used in this context, it is a useful lens through which to view COS and to evaluate their potential to succeed or fail. ANT has been widely used to help analyse socio-technical problems, such as the adoption of the Internet by older people (Tatnall & Burgess, 2002). This section of the paper is a brief summary of the lexicon of ANT. The application of ANT to COS and VCOS is detailed in the following section.

8.1 Actors and Actants

Actors are considered to be the human elements within a socio-technical system, and represent heterogeneous interests, intents and expertise. Actor networks can themselves be seen as actors in other networks and indeed some authors believe that this is inevitable.

Some theorists resist the use of the word “actant”, but it has generally become part of the ANT vocabulary. Actants represent the non-human elements within a network, and as such represent any physical entity that interacts with the network as a whole – both actors and other actants. (“Actant” has been used to describe both human and non-human elements in a network, but this is no longer common.)

Embedded in the principles of actors and actants are the concepts that they will both act with “intent”, and that both assume, or are delegated “power”.

8.2 Moments of Translation

An essential element in ANT is the “alignment of interests”. A network cannot exist, or at least persist, unless this alignment of interests is enacted by all actors and actants within the network. Four “moments of translation” are defined in ANT (Callon, 1986). They are:-

8.2.1 Problematisation

In this initial activity someone (or some people) identifies the opportunity or need for a network to be formed (or joined). This opportunity or need is expressed in such a way that other potential actors can identify with it. This then essentially defines the “aligned interests” of the group, without which the group will have no direction and will, ultimately, fail in its purpose.

8.2.2 Interessement

In this second activity the interest of the potential actor is engaged, and the “terms of engagement” are negotiated. As the community evolves and grows, new actors will automatically fill the generic role of “participant”, but specialist roles may evolve, and existing and potential new actors will need to be allocated to these roles. A critical step in *interessement* is the commitment of the actor to align interests with those already established by the network.

8.2.3 Enrolment

This activity involves enactment of those aligned interests. Given that certain roles have been allocated to, and accepted by, actors in the previous step, actors now perform those roles.

These three activities are performed by all actors as they join the network, and may be performed several times as the network evolves. This is not to say that these activities are consciously engaged in, not that they are assigned to actors at any stage. Rather they are intrinsic steps that are inevitably performed as actors join and realign themselves with, actor networks, and as those networks themselves evolve.

A final step is performed by the network as a whole, rather than by individual actors.

8.2.4 Mobilisation

Having established a community or actor network, it is now time to grow it. Actors should be encouraged to enrol other people into the network, or even start their own (hopefully related) networks.

An “obligatory passage point” (OPP) is considered as essential in the alignment of interests process (Callon, 1986). This can be considered to be a point of “inevitable commitment” – without passing through the OPP, actors never truly join this particular actor network.

9 An ANT analysis of COS and VCOS

The principle actors involved in F2F COS and VCOS are largely the same. Supportees and supporters, in their various guises, comprise the bulk of the population of a COS. Generally the person who first proposed starting the COS (the convenor), and the one (usually) most interested in its continued successful operation, will be considered to be the “focal actor”, although many focal actors can exist with a network, acting as focal points for various sub-networks. Several such sub-networks have evolved from the original F2F support group. In general they are supportive networks such as coffee groups, walking groups, etc. A whole new F2F COS has been started as a result of people’s involvement in the VCOS. Within the VCOS itself, a number of people have started specialised “groups” within the social networking environment, and have thus become focal actors of their own sub-network. However, there has been at least one instance where someone decided to start their own F2F support group in “competition” to the existing group. This was clearly a case of that person wanting to “re-align” the group’s interest to that of their own. Although some people may have switched groups, it seemed as if the majority felt that the existing interests were sufficiently aligned with their needs, and they stayed. It is unfortunate that issues of ownership (i.e. power) arise in such situations; it would be much more productive to promote co-operation. The absence of a clear focal actor is predicted by ANT to be fatal to a successful actor network. If the focal actor leaves the network (or ceases to operate as the focal actor), it is essential that someone else takes over that role, in which case the whole process of establishing aligned interests and the four moments of translation may have to be repeated. Perhaps one of the reasons for the continued success of our F2F group is the fact that there has always been a definite focal actor (even though the person changed), and that the interests of the group have been steadily maintained in such a way that new actors pass through the moments of translation and reach the OPP very easily.

Actor networks can themselves be seen as actors in other networks. Thus, other support groups, the clinics where the groups meet, and the medical profession in general are all important actors in the support group context. Although these associated networks have little direct influence on the original network, there is a definite link between them that is mutually beneficial - an alignment of interests again.

Latour (n.d.) describes actants (non-human actors) as "...literally anything provided it is granted to be the source of an action". There are some distinct differences between F2F COS actants and VCOS actant. In a F2F COS, the only significant permanent actant is the room in which the group meets. The ambience of the room is important, but not critically so, as long as it is suitably equipped for the appropriate number of people, i.e. chairs, lighting, ventilation, etc., all of which have, at various times, given problems in F2F meetings. More important is the room's location – the participants should not have to travel great distances to attend meetings and the location itself should be secure. With a VCOS, all elements of the technology implemented to deliver the service are actants. Whilst actants themselves do not have "interests" and cannot, as non-humans, be described as aligning themselves to anything, the interests of the network are naturally embedded in them. Thus the human-computer interface (HCI) presented to the user, the computer itself, the Internet (in particular the connectivity thereto), the website hosting the community software, and the software implemented to support the group must all align to the network's established interests. Some of the problems associated with these actants are issues of language and cultural compatibility, ease of access and navigation, reliability, speed of operation and response, and the range of facilities and options offered. There are some non-obvious actants as well. For instance, the advertising that we do in terms of flyers, radio and press interviews and so on are actants in the sense that they participate in the moments of translation. If any of these actants carry a non-aligned interest they become a threat to the network's stability.

VCOS have some additional actors acting mainly in roles imposed by the technology used. Firstly, there will (most likely) be a webmaster, tasked with keeping the website running, keeping the "look and feel" of the HCI current, answering technical queries, etc. There may well also be a moderator involved (or even more than one), whose job is to moderate submissions to the various communications channels such as blogs, and even to intervene in antisocial behaviour in, for instance, chat rooms.

In the case of both F2F COS and VCOS, the initial focal actor will almost certainly be the convener of the group. In a F2F group, this person often acts as the "resident expert", whose expertise may be either professional or experiential. This imbues this actor with a power that other actants do not have (in that particular network) or at

least may not be able to adequately exercise, which may cause conflict. However, as Fox (2000) points out “[W]ithout power nothing is achieved”. Thus the use of this power has to be very delicately handled, and its misuse could well be disastrous to the network.

In F2F groups, it is relatively easy for another actor to take over the role of focal actor should the initial focal actor withdraw from the group. However, that new person must be aware of, and be comfortable with, the fact that they are becoming the focal actor of the group, with all of its social and administrative responsibilities. In the VCOS scenario, the problem is much more complicated. Firstly, the convener, webmaster and moderator may or may not be the same person. Indeed, they may not in some cases even know each other, except through their technological roles. If the roles are combined in a single person, there is little problem, except for the same continuity issue as discussed above. However, if two or three people share these roles then issues of “ownership” will arise, and each “owner” will try to take on the role of focal actor. There should be only one focal actor in a network, otherwise separate agendas can arise, affecting the “moments of translation” (see later).

Tang and Yang (2006) identify three emergent roles of participants in social groups, being “opinion-leaders, regular users and isolates”. The focal actor is the natural opinion-leader (although there may be others, which may at some stage become a cause of conflict), but may not always be the “communication star” (*ibid*), in other words, the most “connected” person in the group.

There is a tendency, even a desire, to let virtual groups manage themselves. This is done in the name of “sustainability”, the feeling that a group must develop an ethos and momentum of its own. In this case, the system (website) itself tends to become the focal actor, but being a non-human actant it can have neither “intent” nor “interests”, and ANT (by definition) predicts that such a network will fail. This may not always be a bad thing, as networks are known to dissolve and reform in other guises from time to time. The concern is that in a COS (and VCOS), people may become dependent on the network as it is, and change in such a case may well be a threat to both the network and to certain individuals within that network.

As can be seen from the above ANT analysis there are many reasons why a COS might fail. Fortunately, most of these can be circumvented.

ANT shows that there must always be one, and ideally only one, focal actor in any given actor network. The focal actor establishes and maintains the aligned interests of the network, thus the absence of a focal actor (even if it is only a perceived absence) may result in a drift in those interests, a consequence of which could be the

abandonment of that network. This of course may result in several spin-off networks that may in themselves become successful, but the original goals of the network will have been lost, or at least modified. More than one focal actor can lead to a conflict in interests, thus dividing the community. This has already happened in the existing F2F support groups, where individuals have attempted a “coup” to try and wrest control from us. However, new focal actors made it very obvious that they had their own particular agenda that they wanted to instil into the group that went against the already established aligned interests of the group. It is both possible and highly recommended to have at least one “reserve” focal actor (as seen in corporate succession planning), thus facilitating continuity should the actual focal actor be for some reason unavailable. (Attempts have been made to recruit members to this role, but have so far those attempts have been unsuccessful.) The focal actor, through the problematisation and interesement phases, stamps a particular personality on the community, which seems to be difficult for someone else to sustain. The way forward may well be to re-establish the group with a new identity.

ANT also asserts that any actants identified are equally as important as actors in a successful network. In a F2F community this is relatively easy to achieve. The only significant actant is the meeting room, which can be held reasonably constant in function and appearance for long periods of time. A very distinct change in group dynamics was observed when the meeting venue was changed, and when occasionally a different room has had to be used. There are however many actant elements that need to be considered in a VCOS. Perhaps the most important of these is the human-computer interface (HCI). A means needs to be found to make the interface as generic as possible to accommodate the widest possible spectrum of users. Ideally, the interface should be able to detect and accommodate various user moods, and must accommodate various language, cultural and ethnic groups seamlessly.

The lack of positive individual identity on the Internet is a critical area of concern. With no positive identification of cultural, ethnic, socio-economic or geographical affiliations being available, it is quite possible to offer inappropriate or offensive support to participants in a VCOS. Although almost any topic of conversation is allowed in the F2F group meetings the topic of religion discouraged. Many bipolar supportees experience (sometimes extreme) spiritual episodes if they become psychotic, and talking about these experiences may be offensive (or at least bewildering) to someone of a different religious persuasion. Similarly, suggesting visiting a psychologist to someone who comes from a poor family may come across as elitist.

Communicating across time zones is definitely unique to virtual communities. In a F2F COS, questions and answers occur in real time, facilitating a truly interactive experience for participants. The disjoint communications style of Internet technologies such as email, blogs and discussion groups, and even to an extent chat rooms (inasmuch as threads of conversations can be seen, and responded to, for some time after the interactive session has ceased) has both merits and demerits. On the positive side it allows for a time lag between messages, promoting thoughtfulness and reflection, and this makes the moderation process much easier. However, it does mean that there may be a substantial temporal break in the communication chain if no one else from that physical area (or at least time zone) is currently active on that Internet site. This could prove disastrous in cases where, for instance, someone is in severe trouble, perhaps suicidal, and reaching out for immediate help. Even if someone else is active, if they are from a different geographical area it may be very difficult for them to intercede.

Although the language of communication is unlikely to be a problem (it is unlikely that anyone would join a community whose language they do not understand), the use of metaphors and colloquialisms can be problematic. For example, South Africa is a multi-lingual country, and in Cape Town alone four languages are in common use. The groups are run in English, but occasionally the discussion has to move to one of the other languages temporarily in order for some people to be able to express themselves (especially on emotional issues). Fortunately, enough of the Cape Town group attendees are multilingual enough to be able to translate “on the fly”. Black African culture scarcely recognizes mental illness at all, and groups all such illnesses into one word (“mahlanya”, or “mad”). Thus these Africans often struggle with expressing the subtleties of their illness even in their own language, as there are simply no words in their vocabulary for such things.

The communication of mood is also a problem. In a F2F group this is achieved as much by nonverbal communication (body language) as by oral communication (Henley, 1977). Many Internet systems offer the use of mood-expressive tools such as avatars, “smilies”, and “emoticons”. However, it is clearly possible to fake emotion through these tools, and the typed message may give away contrary emotional indicator to other participants, resulting in mixed messages. The up-and-coming video chat room technology will go a long way toward solving this, but of course, its use will almost certainly never become compulsory in a group.

10 Findings

Communities of support, under certain circumstances, can and do form stable networks. They are worthy of being considered as specialised networks rather than as general communities of practices because of the several different perspectives that participants necessarily have of the practice. The membership, or at least the active participation in these COS is variable, dependent on many things from, for example, the weather (F2F), to how much bandwidth the participant has (VCOS), to the current health state of the supportee (general). Active participants align their interests with those of the existing community, and pass the obligatory passage point by joining in the activities of the community, either by attending a F2F meeting or posting in a VCOS. Occasionally new interests may be expressed amongst members that may result in either a change in the aligned interests of the existing group (growth), the formation of supplementary networks (expansion), or the formation of competitive networks (competition). The former two are generally constructive, but the latter can lead not just to the failure of the original network, but can make future networks more difficult to form.

Failure for a network to form or persist can be attributed, *inter alia*, to:

- a) the lack of a focal actor;
- b) the inability of the focal actor to define the interests of group in a way that attracts other potential members;
- c) the inability to find others to join the community;
- d) the inability to enact the interests of the group (to create an OPP).

These points largely explain why COS fail to be stable, or to start at all, in small communities.

The technology used to implement a VCOS is vital to its success. Poor response times, poor implementation of the HCI, poor content (and behaviour) moderation and lack of platform stability all contribute to members ceasing to participate online.

11 Further research

There is no doubt that the need for COS will persist. As information and communication technology (ICT) extends its reach and capabilities, it is reasonable to assume that increasing numbers of VCOS will form. The nature of VCOS is to discuss matters of an extremely personal nature, often extending to potential life and death situations. Thus the identity, authenticity and intent of participants need to be ensured, something which at present is very difficult to achieve. The HCI needs particular attention if it is to accommodate the various cultural needs of a global network. Similarly, given the nature of COS, the HCI needs to be able to at least indicate participant mood, and preferably to sense it. Many VCOS are implemented in commercial platform such as “ning.com”, but this places the control of many of the non-functional and domain requirements of the platform in the hands of people and organisations who do not share (have not aligned themselves with the) interests of the VCOS. A generic specification for a VCOS would help implementers to better choose or design VCOS platforms.

12 Conclusion

A large and increasing number of Internet users search for and use health related information, and many of these participate in online support groups. These support groups include professional led groups, patient led groups, or apparently leaderless groups. They cover issues ranging from chronic illnesses such as cancer and mental health, to for instance the latest fad diets and cosmetic surgery crazes.

Although the principles of COP cover many of the needs of a mental health support group, they do not cover all aspects that health support groups need, especially those involving empathetic, sympathetic and supportive actions. The cross cultural issues, the issues of providing sympathy, empathy and support and the issue of not all members being occupied in the same practice are all divergences from COP. To this end the concept of a COS is hereby proposed.

Experienced gained with both F2F COS and VCOS shows that actors do indeed align their interests to those of the network. The power role played by the focal actor should not be underestimated, and since the loss of the focal actor may well lead to the dissolution of the network, a succession plan for the focal actor needs to be considered, at least in health related COS.

The analysis of online communities using actor network theory shows the danger of allowing the technology to become the driving force for an online support group. The actant of “meeting place” needs to be carefully considered in both F2F COS and VCOS. Just as the locality and ambience of the physical meeting room is important, so are the availability, accessibility and usability of the HCI of the VCOS. Many networks have made the mistake of thinking that the fancy graphical interfaces and features will be enough to entice users to, and keep them at, the site. ANT predicts that a human actor must act as the focal actor for all networks otherwise the network will ultimately collapse. The HCI is critically important if an online group is to breach traditional national and demographic boundaries. For instance, unwarranted advertising (especially pop-up adverts) may bother some people. Even the colours used in the screen, the form of certain icons and the wording of text needs to be carefully considered in the light of cultural sensitivity and with due regard to the possible mood state of the user.

13 References

- Burnett, G. & Buerkle, H. (2004). Information exchange in virtual communities: A comparative study. *Journal of Computer Mediated Communication*, 9(2).
- Callon, M. (1986). Some elements in a sociology of translation: domestication of the scallops and fishermen of St. Brieue Bay. In Law, J. (ed), *Power, Action and Belief*. Routledge, London.
- Coakes, E. & Smith, P. (2007). Developing communities of innovation by identifying innovation champions. *The Learning Organization: The International Journal of Knowledge and Organizational Learning Management*, 14(1):74-85.
- De Souza, C.S. & Preece, J. (2004). A framework for analysing and understanding online communities. *Interacting with Computers*, 16: 579–610.
- Fox, S. (2000). Communities of practice, Foucault and actor-network theory. *Journal of Management Studies*, 37(6): 853-867.
- Garber, D. (2004). Growing virtual communities. *International Review of Research in Open and Distance Learning*, 5(2).

- Henley, N.M. (1977). *Body Politics: Power, sex and nonverbal communication*. New York: Simon & Schuster.
- Hersberger, J.A., Murray, A.L. & Rioux, K.S. (2007). Examining information exchange and virtual communities: An emergent framework. *Online Information Review*, 31(2), 135-147.
- Huntingdon, P., Nicholas, D., Homewood, J., Polydoratou, Gunter, B., Russell, C. & Withey, R.. (2004). The general public's use of (and attitudes towards) interactive personal digital health information. *Journal of Documentation*, 60(3), 245-265.
- Kyrouz, E.M., Humphreys, K., & Loomis, C. (2002). A review of research on the effectiveness of self-help mutual aid groups. (Updated Chapter 5, American self-help clearing house self-help group sourcebook (7th ed.), White, B.J., Madara, E.J. (eds), 2002. (Publisher unknown.)
- Latour, B. (n.d.) *On actor-network theory: a few clarifications plus more than a few complications*. <http://www.cours.fse.ulaval.ca/edc-65804/latour-clarifications.pdf> (accessed on 27 May 2009)
- Lave, J. & Wenger, E. (1991). *"Situated learning: legitimate peripheral participation"*. Cambridge University Press: England.
- Leimeister, J.M. & Krcmar, H. (2005). Evaluation of a systematic design for a virtual patient community. *Journal of Computer Mediated Communication*, 10(4), article 6.
- Lin, H. (2007). The role of online and offline features in sustaining virtual communities: an empirical study. *Internet Research*. 17(2):119-138.
- Marziali, E., Damianakis, T. and Donahue, P. (2006). Internet-based clinical services: virtual support groups for family caregivers. *Journal of Technology in Human Sciences*, 24(2/3):39-53.
- Nicholas, D., Huntington, P., Gunter, B., & Russell, C. & Withey, R. (2003). The British and their use of the Web for health information and advice: A survey. *Aslib Proceedings*, 55(5/6):261-276.
- O'Hara, Kieron; Alani, Harith & Shadbolt, Nigel. 2002. Identifying Communities of Practice: Analysing Ontologies as Networks to Support Community Recognition. <http://eprints.ecs.soton.ac.uk/6522/1/OHara-IFIP-WCC-2002-camera-ready.pdf> [accessed 04 December 2008]

- Oka, T. & Borkman, T. (2000). The history, concepts and theories of self-help groups: From an international perspective. *The Japanese Journal of Occupational Therapy*, 34(7):178-722.
- Porter, C.E. (2004). A typology of virtual communities: a multi-disciplinary foundation for future research. *Journal for Computer Mediated Communication*, 10(1): article 3.
- Preece, J. (2000). *Online Communities: Designing usability, supporting sociability*. Wiley: New York.
- Preece, J. & Maloney-Krichmar, D. (2005). Online communities: Design, theory and practice. *Journal of Computer Mediated Communication*, 10(4): article 1
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M.R. & Rahman, A. (2007). No health without mental health. *The Lancet*, 370(9590):859-877.
- Radin, P. (2005). To me it's my life: Medical communication, trust, and activism in cyberspace. *Social Science and Medicine*, 62(3):591-601.
- Rodgers, S. & Chen, Q. (2005). Internet community group participation: Psychosocial benefits for women with breast cancer. *Journal of Computer Mediated Communication*, 10(4):article 5.
- Sachs, J.D. & McArthur, J.W. (2005). The Millennium Project: a plan for meeting the Millennium Development Goals. *The Lancet*, 365(9456):347-353.
- Somerville, I. (2007). *Software Engineering* (8th ed.). Harlow, England: Pearson Education Ltd.
- Tang, J. and Yang, H. (2006). Emergent user roles and perceived requirements in a socially-oriented community. *Library Review*. 55(8):508-519.
- Tatnall, A. & Burgess, S. (2002). Using Actor-network theory to research the implementation of a BB portal for regional SMEs in Melbourne, Australia. *15th Bled Electronic Commerce Conference*. Bled, Slovenia, June 17 - 19, 2002. 179-191.
- Wenger, E. (2004). Learning for a small planet: a research agenda. <http://www.ewenger.com/research/index.htm> [accessed on 31 May 2009].

