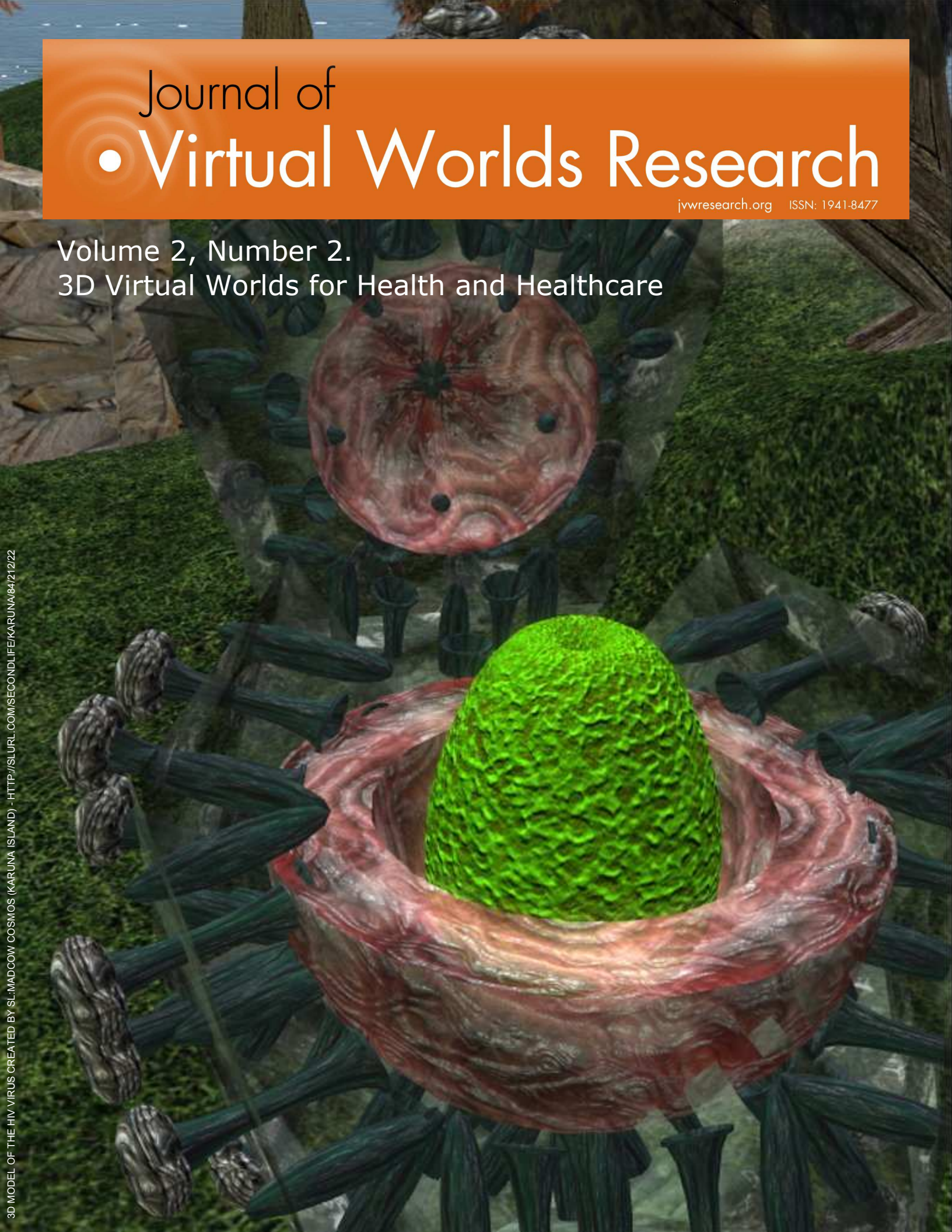


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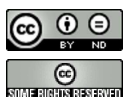
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The Growth and Direction of Healthcare Support Groups in Virtual Worlds

By John Norris, Albany, Oregon

Abstract

What is the growth and direction of healthcare support groups grow in virtual worlds? Data was collected on over 300 groups from virtual worlds, including Second Life®, IMVU, There, and Kaneva. Similar categories of groups were found to be generally popular across worlds. The percentage of groups in categories of healthcare issues was also generally analogous between worlds. The long tail effect was shown- only a few groups had high populations. Group creation rate displayed generally similar growth between worlds. The worlds' demographics and features were suggested to account for differences. Limited data availability and vague definitions of groups and categories hampered analysis.

Keywords: Second Life;IMVU; There; Kaneva; Support Groups; Healthcare.

The Growth and Direction of Healthcare Support Groups in Virtual Worlds

By John Norris, Albany, Oregon

This article reports a study that explored the growth and direction of healthcare support groups in virtual worlds. The article begins with a brief definition of healthcare support groups in virtual worlds, and then focuses on four virtual worlds: Linden Lab's Second Life® (secondlife.com), IMVU (www.imvu.com), There (www.there.com), and Kaneva (www.kaneva.com). Each virtual world is discussed in terms of its general characteristics and themes, and analysis includes possible reasons for the direction of growth in each world's healthcare support groups.

A support group is "a group of people with common experiences and concerns who provide emotional and moral support for one another" (*Merriam-Webster*, 2009.) Note that this does not require that didactic or expository information will also be exchanged regarding their mutual concern. A simple chat type group may offer support. By healthcare it is meant, "the prevention and treatment of illness or injury, esp. on a comprehensive, ongoing basis" (*Webster's*, 2009). Note that this does not require a licensed professional. Non-professionals and peers may also provide healthcare. "Virtual worlds" may be defined as including three characteristics: (1) they are a common areas that people can network into and share; (2) they exist whether people are logged in or not; and (3) people are represented by avatars- allowing them to interact with the environment of the virtual world and each other (Koster, R. (2007.) Thus, a healthcare support group in a virtual world consists of a number of individuals that communicate health-related supportive messages using the various features of their networked, persistent space through the use of their avatars.

There are a wide variety of virtual worlds. For this study, worlds that are not new were selected, as they offer richer historical data. They are also oriented towards young and older adults that from this author's perspective are more likely to discuss matters of healthcare (K Zero, 2009)

Second Life®

Background

Second Life®, by Linden Lab, began in June of 2003. Its theme is "a world of exploration, socializing, creativity, self-expression, and fun unlike any other" (*Your Second Life®*, 2009). Second Life® includes free membership.

Those who use the adult Second Life® grid need to be 18 years and older. As of the 4th quarter of 2008, there were 15 million users of second life (*K Zero Universe*, 2009.) The largest group of users are from the U.S. but amount to just 39% of the total. The average age of users is around 40 and almost 60% of the users are male ("Second Life® Virtual World Expands", 2008.

Method of Data Collection

The study looked only at those groups in Linden Lab's Second Life® adult grid. To identify healthcare support groups in Second Life®, its in-world search feature was used. A list of possible groups was obtained from the website [SLHealthy](#) and these words were used to perform a search. An additional search with the keyword "support" was performed via Linden Lab's Second Life® inworld search feature, using the "groups" tab. A total of 152 groups were identified. Data was collected about them from their inworld group information search page.

However, when doing the "support" search, Second Life® did not allow the viewing of more than 100 pages of results. Of the approximately 2000 returned items from that keyword search, only the first 1000 were viewable. Because the healthcare support groups accounted for 15% of the first 1000 groups, if there are more results, the number of unaccounted for support groups may be significant. The 152 groups that were identified may not be a complete list.

The 152 groups were organized into categories of healthcare issues based on the taxonomy of the American Self-Help Group Clearinghouse.(E White, Madara 2002). This enabled a broad overview of trends within worlds as well as a more general cross comparison between worlds.

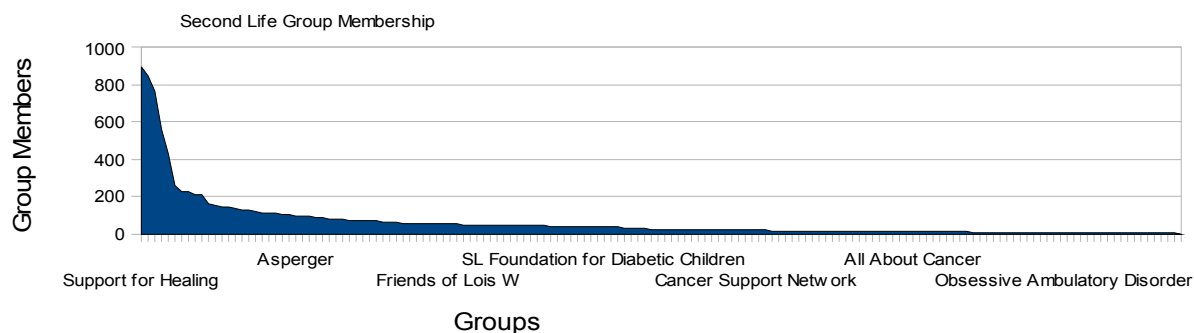
Results and Discussions

Total Membership

The groups collected had a total of about 10,000 members. However, since each avatar can join up to 25 groups and a person can have multiple avatars it is difficult to identify how many individuals may be participating.

Membership per Group

The following graph shows the group membership of all 152 groups. Only some of the group names are shown.



Of the 152 groups only 25 of them have one hundred members or more, and there are over 50 groups with less than a dozen members. Chris Anderson dubbed this the "long tail effect" (Anderson, 2004) because the Internet allows people to publish things cheaply. Thus

niches that only appeal to a few people and would never be able to make it in old, expensive media, flourish on-line.

For a healthcare support group, this is a boon, in that it allows those with rare diseases to interact with each other. However, in a larger sense, it also allows people with unique approaches to their issues to interact with each other. Thus, there are 19 groups concerning cancer and 17 groups for autism/spectrum disorder. This suggests that people are making or finding groups that they feel comfortable in.

Groups with the most membership:

It is instructive to look at the top five groups with the most members. I will include a brief description for some:

- (1) *Support for Healing* 899 members (Mental health and other issues)
- (2) *Transgender Resource Center* 845 members (Gender identity issues.)
- (3) *Positive Mental Health* 763 members
- (4) *Wheelies* 565 members. (Disabilities themed nightclub.)
- (5) *Depression Support Group* 427 members issues.

Other groups with significant memberships include:

- (6) *Dream Travelers* 258 members (Stroke and Autism Spectrum Disorder issues.)
- (7) *Breast Cancer Awareness* 224 members
- (8) *SL's Cancer Survivors* 210 members.
- (9) *Autistic Liberation Front* 207 members.
- (10) *SL Deaf Underground* 162 members.
- (11) *Aspies for Freedom* 147 members (Aspergers Syndrome).
- (12) *Asperger Awareness* 131 members.

Categories of Groups:

All 152 groups were placed into healthcare issue categories and their percentages of the whole noted.

Abuse: > 1%
Addictions 5%
Bereavement 4%
Disabilities 20%
Family 0
Health 49%
Mental Health 15%
Miscellaneous 5%

The "Health" category includes almost half the groups, but this is not too surprising given how general of a category it is. Not only does the Health category have many of the groups, it also includes many groups that are concerned with a particular issue or diagnosis. The issues

with the most groups are Cancer (19 groups), Autism/Spectrum Disorder (17 groups), Addiction and "Mobility" (7 groups each), HIV (6 groups), and Bereavement (5 groups). This shows diversity around at least these issues. It may show that individuals are involved with groups that resonate within their unique selves.

Membership in Group Categories

Membership in each category of group as a percentage of total membership, shows a different breakdown:

Abuse: > 1%
 Addictions 2%
 Bereavement 1%
 Disabilities 25%
 Family 0
 Health 40%
 Mental Health 32%
 Miscellaneous 2%

While Bereavement counted for 4% of the groups, it only has 1% of the total members. Perhaps this shows that such an issue brings out more varieties of approaches. Mental Health counted for 15% of the groups but 31% of the total members. This would seem to indicate the opposite of Bereavement. Perhaps when dealing with the subject of mental health more people feel comfortable in fewer groups, and so unique approaches are not brought out. However, the group with the most members, Support for Healing, has several sub-groups within it, that use different approaches, but whose membership is counted in total. Further, some Mental Health groups may need a critical mass in order to be available at all hours to help respond to their member's immediate needs.

IMVU

Background

IMVU began in 2004 ("About," *IMVU*). Its theme is an Instant Messaging Service (Terdiman, 2004) with a heavy graphical user interface. It is a 2.5d type space which is room based; one does not really walk around much. Indeed, the focus on developing IMVU has been on avatars and not on land (Caoili, 2008). It includes free membership. IMVU also offers an online web based forum along with its in-world offering.

Those who use IMVU need to be at least 13 years or older. They had 22 million users as of the end of 2008. Forty percent of their users are from the US. The 'core' users are 18 to 24 years old ("Frequently Asked Questions," *IMVU*).

Method of Data Collection

In IMVU groups are listed in categories. Data was collected on November 23rd and 24th from the “Real Life/Health” list of groups from IMVU.com. Of the 331 groups IMVU listed in that Health subcategory, the study identifies 142 as being about healthcare. Some of the group’s details suggested that at one time, in-world payment was given to people if they started a group. This would skew some of the data.

The study found a large number of seemingly simple ‘chat’ type groups within this health category. Many had no firm theme and only a modest amount of members. It is difficult to be sure what sort of health issues these should be understood to be dealing with. The study identifies that for 142 health groups, 13 (or roughly 10%) are chat groups. The study places them into categories, including Miscellaneous.

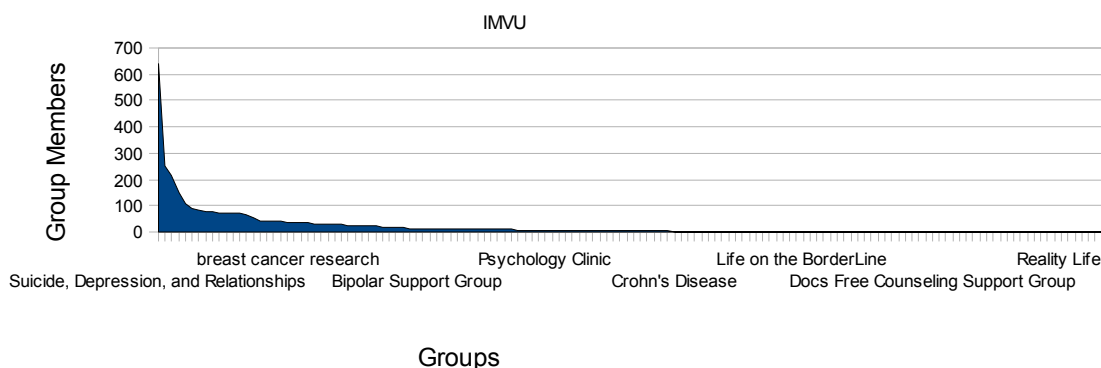
Results and Discussions

Total Membership

For all health groups identified, including those that seemed to be simple chat groups, there are 3270 members. Because 'chat' type groups account for over 1000 members, these groups were included in the analysis. Because individuals can be members of multiple groups and have more than one avatar, it is difficult to know how many people are actually involved.

Membership per Group

The following graph shows the membership level of all 142 groups. Some of the group names are shown.



The graph displays the long tail effect. Of the 142 groups only 5 had over 100 members. 86 groups had 10 members or less.

Groups with the most membership

Here are the top 10 groups with the most membership. Brief details for some are included.

- (1) *Suicide, Depression, and Relationships* 639 Members
- (2) *<Be Yourself!>* 254 Members (An example of a simple chat group. A place to talk about general issues, or just chat.)
- (3) *Suicide Awareness* 217 Members
- (4) *Fibromyalgia* 152 Members
- (5) *Soul ~ Heart ~ Mind ~ Body & Holistic Health* 111 Members ("Ancient" ways towards wellness.)
- (6) *Tickle me Pink* 91 Members (Cancer issues)
- (7) *Pregnant Teens* 83 members.
- (8) *Straight Edge* 83 members (Part chat, part healthy lifestyle.)
- (9) *Mental Health Survivors* 76 members.
- (10) **Helping and Sharing Medical Advises* 74 Members.

One group, the *Suicide, Depression, and Relationships* group, has far more members than the next. While it is categorized as a Mental Health group, the inclusion of relationships may allow them to pull people interested in the more general type chat groups. General type chat groups are quite popular in IMVU. Several of those general chat groups are in the top 10 groups.

Types of Groups

Abuse 2%
Addiction 3%
Bereavement 0
Disability 11%
Family < 1%
Health 31%
Mental Health 19%
Miscellaneous 37%

General chat groups were placed in Miscellaneous and that category accounts for most of the groups.

Members in Group Types

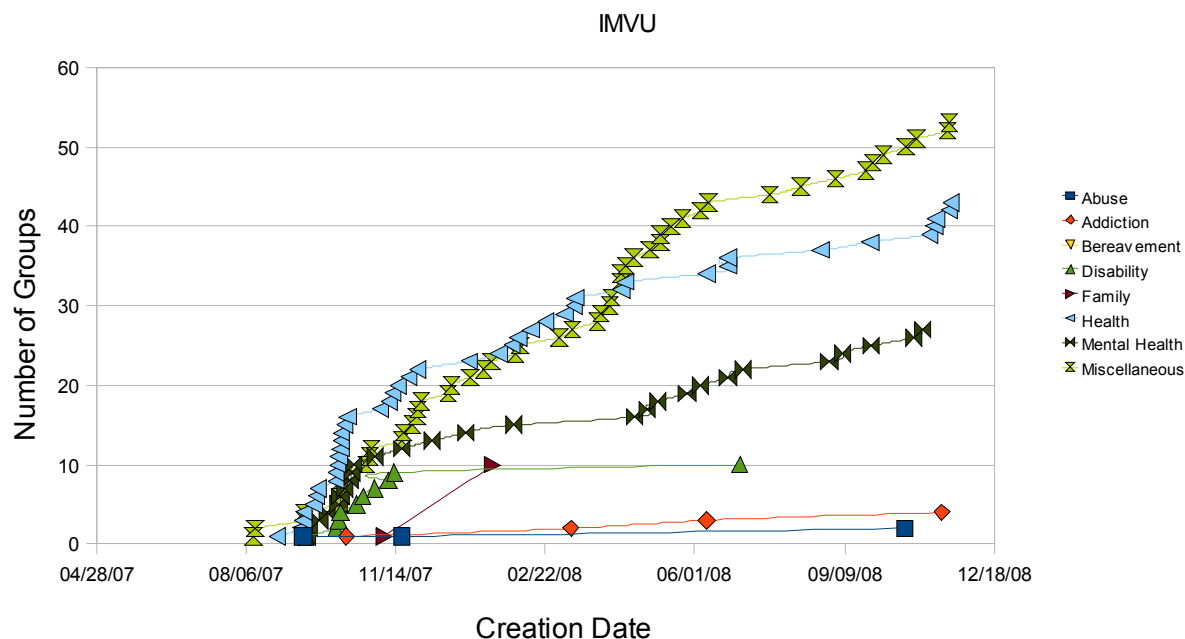
Abuse 3%
Addiction 1%
Bereavement 0
Disability 5%
Family 3%
Health 24%
Mental Health 38%
Miscellaneous 27%

However, the mental health type groups have more members. This is mainly due to one group - *Suicide, Depression, and Relationships* - being included in Mental Health and perhaps giving a false impression.

While groups concerned with disability account for 11% of all groups, their memberships are only 5%. This would mean that unlike other group types, Disabilities has many more groups with fewer members. Perhaps for IMVU, the unique nature of individual disabilities make for a wider variety of groups.

Group Growth

IMVU group information includes their beginning date. This makes it possible to graph the growth of the number of groups in each type over time. Note this graph only shows groups created in each category not whether the groups are still active.



The graph shows the rapid increase in most group categories in late 2007. After a month or so, there was a lessening of most category growth rates. Perhaps this rapid increase was from the pent up demand prior to the ability to create groups. The quick accumulation of groups may have also been due people caught up in the general excitement of group creation. Perhaps some people were inspired to create groups whom normally would not, or others created more than one.

For the categories Miscellaneous and Mental Health there is a bit of a secondary increase in early to mid-2008. This may be due to policy changes at IMVU that rewarded people who created groups. From the data collected it was not clear precisely when that might have occurred, but by late 2008 it was no longer IMVU policy. This secondary increase may also have occurred during a rapid influx into IMVU in general; however, that data was not collected.

To a lesser extent the Health category also experienced a secondary increase, but at an earlier time. Perhaps there are other factors also at work. Perhaps these are people who had joined a group, but then decided later to create their own.

The Disability category saw a similar quick rise, but then almost nothing after that. Disability had a lot of groups, but with fewer members. Perhaps there were not enough members to sustain such groups.

THERE

Background

The virtual world There went off beta in 2003. Its theme is more of " a 'hang-out' social destination than a creative platform, although content creation and in-world currency (therebucks) are both available (Mitham, 2007). It includes free membership. The world of There also offers an online web-based forum along with its inworld offering.

Those who use There need to be over 13 years of age (Mitham, 2007). They have 2 million registered accounts as of the 4th quarter 2008(*K Zero Universe*, 2009). The average age tends towards the early 20's (*K Zero Universe*, 2009), but 32% are between 13 and 17 (Mitham, 2007). Finally, 46% of the members are female.(Mitham, 2007)

Method of Data Collection

In the world of There they also list their groups in sections. On January 10, 2009 the There Forum's Health and Wellness section lists 235 groups. Despite being within the category, many groups did not describe themselves as being about healthcare. For example, there is a group called "People who like cake", and another called "People who can't stop singing the "NumaNuma" song". The study identified 48 groups that seemed to be about healthcare including some simpler chat type groups. The more general chat groups were included in Miscellaneous.

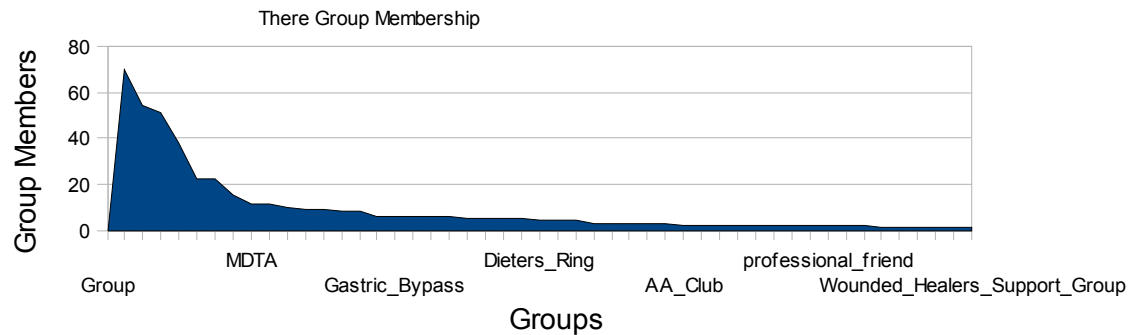
Results and Discussions

Total Membership

The 48 groups had a total of 443 members. Note that individuals can join multiple groups and can have more than one avatar, making it difficult to discern how many people are involved.

Membership per Group

The following graph shows the membership level of all 48 groups. Some of the group names are shown.



The first 3 groups each have over 50 members. The last 28 groups have less than 5. This graph shows the long tail is also in effect in the world of There.

Groups with the most membership

What follows is the top ten groups in There. Shown are the membership totals, plus a few details to help understand the nature of some groups.

- (1) *Disability_in_There* 70 members
- (2) *Deaf_People_R_Not_Ignorant* 54 members
- (3) *Find_a_Cure* 51 members (Cancer issues)
- (4) *Anxious_Avatar* 38 members (Panic, Anxiety, and other disorders.)
- (5) *Occas_Gym* 22 members (Weight loss and muscle gain.)
- (6) *Seizure_Disorder_Support_Group* 22 members
- (7) *Chronic_Pain_FMS_CFS_etc_Support* 15 members
- (8) *MDTA* 11 members (Muscular Dystrophy Association)
- (9) *Victims_of_Stalkers* 11 members
- (10) *Ask_Mily.....* 10 members (Advice)

As shown above, the top ten groups in There, for the most part, address a variety of fairly specific issues. No one issue seems to dominate this world.

Types of Groups

- Abuse 2%
- Addiction 2%
- Bereavement 0
- Disability 19%
- Family 2%
- Health 49%
- Mental Health 13%
- Miscellaneous 17%

The general Health category identifies almost one-half of the groups, with the rest below 20%. This is similar to the top ten groups list above.

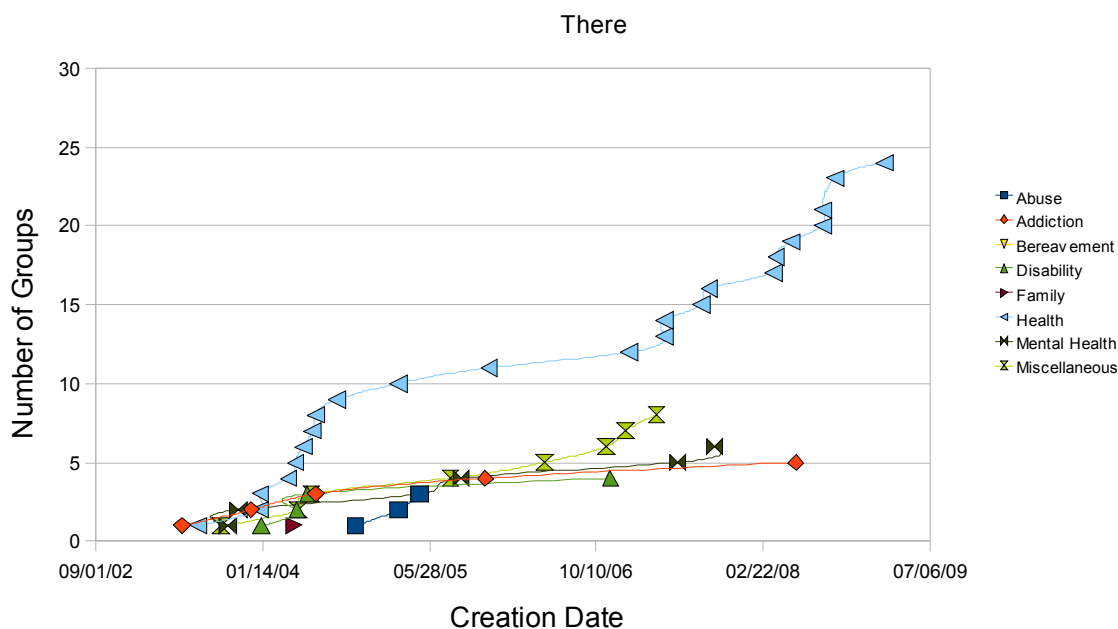
Members in Group Types

- Abuse <1%
- Addiction 2%
- Bereavement 0
- Disability 29%
- Family 0
- Health 42%
- Mental Health 15%
- Miscellaneous 8%

We see in There that the Disability category has numerous groups but significantly fewer membership share. The Miscellaneous category also has fewer members. The reasons may be similar to the ones discussed for IMVU.

Group Growth

The world of There has information about each group's their beginning date. The following graph shows the growth of the number of groups in each category over time.



In the There world, the Health category rather quickly outpaces the other areas. This shows that this world has, from its inception, favored these types of issues. Further, as Health becomes more popular, it comes to the attention of more people, who then may start their own groups. This may be why we see secondary and tertiary increases around 2007 and later 2008. Mental Health and Miscellaneous also have a secondary increase around 2007, so there may be other factors in play (or simply not enough data to warrant analysis). Another possibility is that there was an over-all increase in the population of There. However, this may have not been the case because Disability and Addiction did not also increase at the same time.

Except for those groups in the Health category, few other groups were created after 2007. The world of There may be suitable for those in the Health category, but perhaps not for others.

It is also possible that the other categories have enough groups to address the needs of new individuals. However, the Miscellaneous, Mental Health, and Addiction groups did not have many new members in late 2008 and early 2009. Perhaps people who would normally join such groups are going elsewhere.

KANEVA

Background

Kaneva began in 2007 ("Kaneva Virtual Entertainment", *Kaneva*). It provides "flexibility to easily move back and forth from the 2D web to the 3D Virtual World of Kaneva" ("Kaneva Virtual Entertainment", *Kaneva*). It is "built for the masses" ("Kaneva Virtual Entertainment", *Kaneva*) and is meant to be easier to use than Second Life® (Hopkins, 2007).

Kaneva's membership in 2007 was 800,000 (Schifrin, 2007). I was not able to find more current data. This is a year earlier than the other world's memberships the study cites. Their average age of members is in the early 20's (*K Zero Universe*, 2009). Members need to be 14 years or older ("Kaneva Privacy Policy", Kaneva).

Method of Data Collection

Kaneva has an in-world search feature that was used to look for healthcare support groups. Keywords were based on those used in the data collection for Second Life®. Using this method, very few groups were found. Further groups were identified using the keywords from the index of the book "The Self-Help Group Sourcebook" (White B. J., Madara E., 2002). There were some chat-type groups that included in Miscellaneous. A total of 27 healthcare support groups were identified on January 10, 2009.

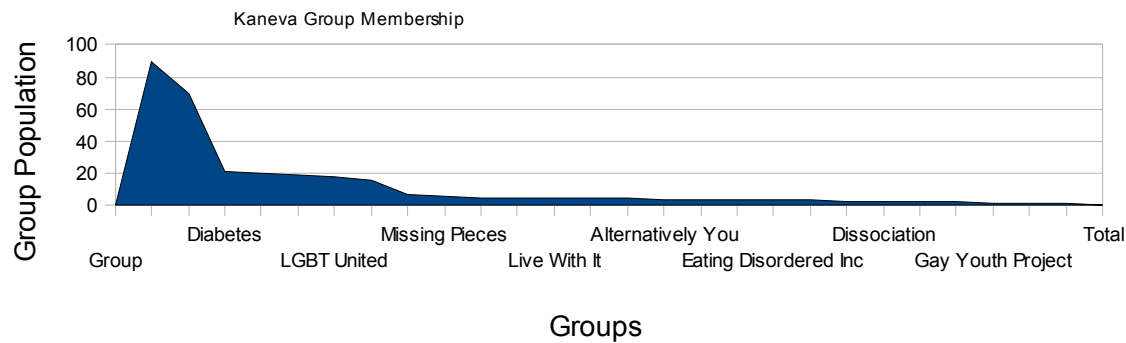
Results and Discussions

Total Membership

The 27 groups had a total of 313 members. That is with the understanding that people can join multiple groups and have more than one avatar.

Membership per Group

The following graph shows the membership level of all 25 groups. Some of the group names are shown.



The top 2 groups each had over 40 members. The remaining groups had 21 or less members, with more than half of the 25 total groups having less than 5 members. This reflects the long tail effect.

Groups with the most membership

Find below the top ten groups with the most membership, including the total number of members, and a brief explanation for some.

- (1) *GBLT- Social and Support Center for Adults* 89 members
- (2) *Kaneva Mafia Cancer* 70 members
- (3) *Diabetes* 21 members
- (4) *Autism Awareness Open Community* 20 members
- (5) *I am Not OK* 19 members (FMS (Fibromyalgia), CFSID (Chronic Fatigue and Immune Dysfunction Syndrome) and similar diseases.)
- (6) *LGBT United* 18 members
- (7) *Starryangelmom Autism Awareness Chatroom* 16 members
- (8) *Deaf Peace* 7 members
- (9) *Missing Pieces* 6 members (Autism)
- (10) *Being a Teen* 5 members

In the world of Kaneva, the top groups predominantly deal with GBLT or autism issues. The study is cautious to draw any firm analysis because of the small data set, but there is something in the Kaneva community that has allowed these issues to come to the fore. It may be the personality of a few major players, more than the features of the world itself.

Types of Groups

- Abuse 0%
- Addiction 0%
- Bereavement 7%
- Disability 26%
- Family 4%
- Health 22%
- Mental Health 7%
- Miscellaneous 33%

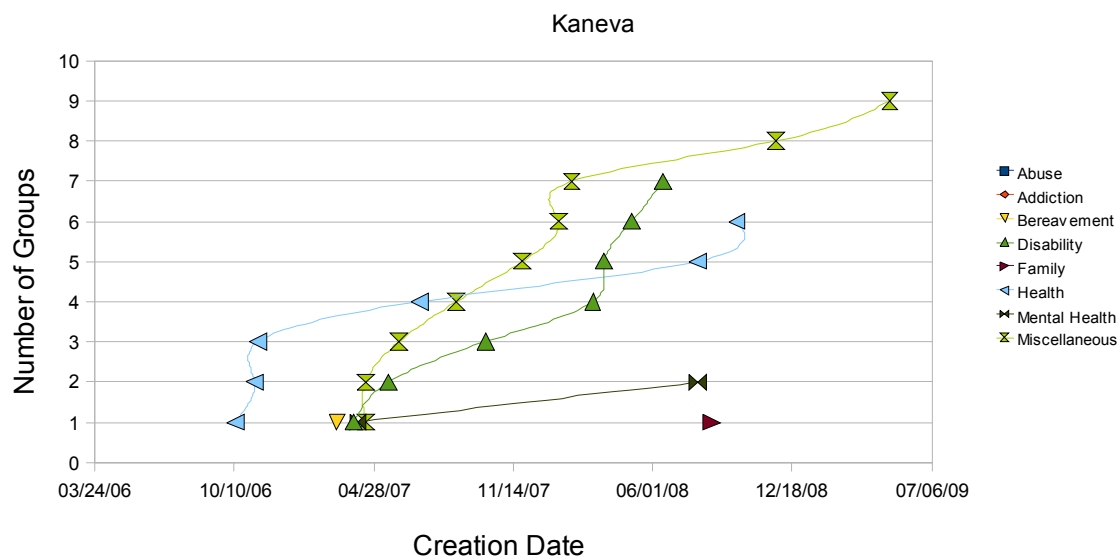
Members in Group Types

Abuse 0%
 Addiction 0%
 Bereavement 1%
 Disability 19%
 Family <1%
 Health 39%
 Mental Health 1%
 Miscellaneous 41%

The amount of members in each group's type is similar to the quantity of groups for that type. Thus, the more popular category of group has more members. One category of group does not seem to be more diverse than another.

Group Growth

Kaneva's group information includes their beginning date. The graph shows the growth of the number of groups in each type over time.



There is an immediate rise in the general Health category, but it is later overtaken by both Mental Health and Disability. Perhaps the early adopters were less oriented towards specific issues, reflecting a general population. However, once Kaneva became better known, those with specific issues decided to call it their home. However, later in time many of the group categories did not have new groups. Only the Miscellaneous groups continued adding groups. Upon checking the Disability and Health groups there seemed to be only a modest amount of new members in 2008. The graph also shows secondary increases in growth rates similar to the other worlds.

Discussion

Prior to a more general discussion, the following is a simple representation of some of the studies findings:

Virtual World Demographics and Healthcare Support Groups (HSG)¹

	Second Life	IMVU	There	Kaneva
Minimum Age Limit	18	13	13	14
Average Age	~40	18-24	~20	~20
Total Users	~15,000,000	~22,000,000	~2,000,000	~800,000
Number of HSG's	152	142	48	27
Total Memberships	~10000	3270	443	313
The Three Groups with the Highest Memberships	Support for Healing	Suicide, Depression, and Relationships	Disability_in_There	GBLT
	Transgender Research Center	<Be Yourself>	Deaf_People_R_Not_Ignorant	Kaneva Mafia
	Wheelies	Suicide Awareness	Find_A_Cure	Diabetes

¹ Please refer to the text for explanation of the statistics

There are many people involved in healthcare support groups in each of the virtual worlds studied. This, in itself, does not speak to the efficacy of such groups. While it is beyond the scope of this paper to make any determination as to the benefit members may derive from the group, a brief look at some studies in this area is helpful.

Past research had lead to the conclusion that the efficacy of online support groups and communities had not been established. Although anecdotal evidence seemed to show that online support groups were helpful, their value was unclear (Eysenbach 2003).

More recent studies show that online healthcare support groups may be effective. One study involving an online cancer support group found that depression, growth, and psychological well being improved over a six month period (Lieberman 2005). A professionally managed online support group concerning diabetes found 74% of the respondents reported that their ability to cope was helped (Zrebiec 2005). Preliminary data suggest that an online support group for women in rural locations with chronic illness helps these women adapt to their condition(s) (Weinert 2005). Sixty percent of the participants in an online dentistry anxiety support group felt their anxiety was lessened (Coulson 2007). Further studies, especially those for groups taking place in virtual worlds are necessary to properly address the efficacy question.

Some work has been done on the specific characteristics of a group that allow an individual to benefit from a group, which helps explain several aspects of what is seen in virtual

worlds. One of the traits identified in real life groups was that members who shared similar norms as their leaders benefited from the group (Lieberman 2004). Another observation from real life support groups is that the norms of the group need to be different from those of the larger society in order to effect change on their members (Lieberman 2004). Further, approaches for some members may not be appropriate for others. One example is a bereavement support that is age and gender specific (Gary 2000). Since the content of real life and online support groups are very similar (Golant 2006), we should not be surprised to see differentiation of groups in virtual worlds.

This helps explain the long tail effect, as people find the groups that best fit them, whose group/leader norms are compatible with their own, and which offer the boundaries from society that help them change. Online support groups allow one to search through or lurk to find the one that best fits with them and matches their needs (Golant 2006). One can more easily find the group that suits them and not join ones that are “good enough”. This point also addresses how different virtual worlds - with their own norms inherent in the platform - can be a positive force for further group differentiation.

Just what those norms are and how they contribute to what type of groups are created needs to be further explored. If more virtual worlds become popular and are populated with healthcare support groups, it may be possible to more formally identify what features encourage or prevent certain types of groups from forming.

A study such as this, identifying specific features across a wide range of virtual worlds, and their corresponding healthcare support groups, may allow one to tailor virtual worlds to successfully address particular healthcare issues. With a better understanding one would also be able to include in-world help for those types of healthcare support groups that one would be expected to be popular.

A subject that was not addressed in this study, but would be an important extension, is the levels of activity for the groups. How often do members meet? How much is information exchanged in a given time period? Which groups no longer function, but are merely listed in-world? Another component to this is how people are distributed across groups. Are there only a few people in many groups or are the groups populated with a variety of individuals?

The present study was hampered to a degree by lack of access to data. Some group data is simply not available without special access. However, using available access, the study provides a preliminary look at a fascinating and important area of virtual worlds.

In each of the worlds studied, people created areas to discuss health. It seems that when communication is available, healthcare is a topic that quickly emerges. The growth charts demonstrate how such groups spring up almost immediately. Even Google's ill-fated Lively had 19 healthcare areas in November 20, 2008, 4 months after it opened and 2 months before it was scheduled to close.

Thus, it is hoped that the present study will provide an introduction toward better understanding healthcare support groups in virtual worlds, in order to create better worlds, support, and tools required for this obvious need.

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