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**Social support in cyberspace: A content analysis of communication within
a Huntington's Disease online support group**

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ABSTRACT

Objective: Huntington's Disease (HD) is an inherited disorder, characterised by a progressive degeneration of the brain. Due to the nature of the symptoms, the genetic element of the disease and the fact that there is no cure, HD patients and those in their support network often experience considerable stress and anxiety. With an expansion in Internet access, individuals affected by HD have new opportunities for information retrieval and social support. The aim of this study is to examine the provision of social support in messages posted to a HD online support group bulletin board.

Methods: In total, 1313 messages were content analysed using a modified version of the Social Support Behaviour Code developed by Cutrona & Suhr (1992).

Results: The analysis indicates that group members most frequently offered informational (56.2%) and emotional support (51.9%) followed by network support (48.4%) with esteem support (21.7%) and tangible assistance (9.8%) least frequently offered.

Conclusion: This study suggests that exchanging informational and emotional support represents a key function of this online group.

Practice implications: Online support groups provide a unique opportunity for health professionals to learn about the experiences and views of individuals affected by HD and explore where and why gaps may exist between evidence-based medicine and consumer behaviour and expectations.

Keywords: Computer-mediated communication, Huntington's Disease, Internet, Social support

1. Introduction

1.1 Online support groups

In recent years, there has been a proliferation of health-related information on the Internet. Moreover, many websites offer communication features which have facilitated the development of online support groups across a variety of chronic illnesses and conditions [1]. These groups are quickly becoming one of the most frequently accessed resources on the Internet. For example, a recent survey undertaken by Pew Internet Research Institute [2] revealed that at least 36 million people in the USA were members of online support groups. These groups function by enabling individuals to engage in supportive interaction through bulletin boards, chat rooms, list-serves and individual email exchanges with others facing similar issues, challenges or problems.

Commentators have established that there are a number of advantages of such groups [1,3-5]. First, they are not restricted by the temporal, geographical and spatial limitations typically associated with face-to-face groups so individuals can send and receive messages at any time of the day or night. Second, the participant is able to carefully consider their message and develop it at their own pace before posting it to the group. Third, online support groups may bring together a more varied range of individuals offering diverse perspectives, experiences, opinions and sources of information than might otherwise be the case. Fourth, participation in an online support group allows a greater degree of anonymity than face-to-face groups. Such anonymity may facilitate self-disclosure and help individuals in discussing sensitive issues more easily or to give opinions with less fear of embarrassment or judgement than in more traditional face-to-face groups [6-8].

1.2 Internet support groups and social support

Although it has been noted that little is known about the nature of online social support [1], there has recently emerged a growing body of research on this

topic. A number of these studies have included content or thematic analyses of existing messages on online bulletin boards [4,9-11]. Results from these studies suggest that the majority of messages on these boards include giving or receiving social support and that informational and emotional support are most prevalent [4,9,11]. However, most of this work has focused on relatively common chronic illnesses, with illness characteristics that are nominally familiar to the wider population (for example, diabetes and irritable bowel syndrome) [4,9]. There are few studies which focus on rare conditions that are not widely understood, such as Huntington's Disease.

1.3 Huntington's Disease

Huntington's Disease (HD) is an inherited neurological and degenerative condition which is relatively rare (e.g. within the UK, prevalence is estimated at 1 per 10,000) [12]. It is characterised by movement disorder, cognitive deterioration and affective disturbances. The mean age of onset for HD is 40 years (with some variation) and as yet there exists no cure, with treatments available being palliative or experimental and death occurring on average 15-17 years after onset [13]. Each child of a person who has HD, carries a 50% risk of developing the disease and is typically referred to as "being at risk". Such a state has often been described as living with an abiding sense of impending threat [14].

The development of a predictive test for HD in 1993 was highly significant for those families affected by HD [15]. The test can determine, prior to the appearance of any visible signs of the illness, whether the mutation is present. The decision to be tested is not necessarily straightforward as it presents a range of challenges not only for the individuals "at risk" but also many others (for example partners, children and siblings). It has been noted that the results of the test carry with them profound implications for the future [16]. The need for certainty, to be able to plan for the future and to inform children are all

commonly cited reasons by “at risk” individuals for decisions to undertake genetic testing [17].

For individuals who develop HD it is generally the immediate family that take on the responsibility of caring. Recent studies have shown that these informal carers frequently subordinate their own needs and quality of life to the needs of their loved ones [18,19]. Moreover, stress and anxiety are common and emanate from their caregiving role [20-23]. In addition, the symptoms and genetic nature of HD makes this carer role distinct from others [24]. Appropriate care is often hard to find and carers struggle to maintain their own identity as the disease process takes over their lives as well as the life of their HD affected relative [25,26]. Loneliness, a sense of loss and lack of support are all commonly observed [18].

Faced with this diverse range of challenges, and with the rise in popularity of online support groups, individuals affected by HD may be drawn to participate in these groups. However, little is known about the nature and type of social support exchanged in this context, and more widely across rare and poorly understood conditions.

1.4 Aim of the study

The aim of this present study was to examine the provision of social support through a content analysis of messages posted to an online support group bulletin board for individuals affected by HD.

2. Methods

2.1 Participants

The research team identified a publicly accessible online HD bulletin board for the purposes of the study. Whilst we identified a number of possible HD bulletin boards the present board was selected due to the volume of messages posted (N=1313), thereby providing a sizeable data set for analysis. In addition, the

present board was the only board which was a non-active archive (see below for discussion of ethical considerations). The board was not moderated and existed to discuss and comment on HD. However, individuals who wished to post a message were required to register. As a result, there did not appear to be any 'spam' messages present within the data set. The participants in this study were all members who posted messages to the board during a 21 month study period (May 1998 – Jan 2000). In total, 793 unique sender names were identified. As a consequence of the anonymous nature of the bulletin board, socio-demographic and background data were limited to that which was offered spontaneously. Among the information, which was offered by group members, was their relationship with HD. There appeared to be a broad spectrum of individuals participating online including: individuals 'at risk' (but who had not undergone genetic testing) (29.3%); individuals in receipt of a positive result (5%); individuals in receipt of a negative result (7.3%); spouses (12.4%), partners (2.5%), friends (1%) and teachers (.02%). Within the spousal group many were caring for a loved one who was symptomatic. In addition, it was possible to determine that 30% were female and 17.3% male.

Previous commentators contend that, personal discourse on the Internet is public and is not subject to human participant constraints thus ethical approval from individuals is not essential [27]. However, we still deemed it appropriate to obtain ethical approval from our internal University ethics committee according to the ethical principles as set out by the British Psychological Society. At the request of this committee, a non-active archive was selected for analysis. From the perspective of HD, there have been no significant advances in treatment or cure in recent years and therefore it would be reasonable to expect that the messages posted to this archived board would indeed reflect current discussions on this disease.

2.2 Procedure and data analysis

The first stage of data analysis consisted of a preliminary screening of all postings (n=1313) for evidence of social support. At this stage, social support postings were broadly defined as those offering caring, belonging, esteem or assistance to the recipient [28-30]. One coder applied this definition to all messages posted to the board. Social support was evident in 98.9% of messages (n=1299).

Content Analysis

Content analysis was employed to examine the provision of social support within the postings to the bulletin board. This method of analysis was selected as a helpful means through which our large data set could be systematically scrutinised and postings categorised according to the social support theoretical framework. In so doing, the aim of this analysis was to examine the manifest content of the postings.

The Social Support Behaviour Code developed by Cutrona & Suhr [31] was adapted for use in this study. It has previously been successfully used as a coding system for the analysis of online support group bulletin board messages [32]. This taxonomy was designed to assess the frequency of occurrence of support-intended communication behaviours that fall into 5 main categories: information support (providing information or advice); esteem support (communicating respect and confidence in abilities); network support (communicating belonging to a group of persons with similar concerns or experiences); emotional support (communicating love, concern, or empathy) and tangible assistance (providing, or offering, to provide goods or services). Moreover, Cutrona & Suhr proposed 23 subcategories within these 5 categories. The research team discussed the applicability of these coding categories, identifying examples for each category, and revising category definitions as appropriate (see Table 1). One subcategory, "listening" was deleted from the coding system as this refers to behavioural characteristics of the listener which is not possible to code within an online

environment. In addition, the subcategory, “physical affection” was modified to “virtual affection” to acknowledge that whilst no actual physical contact took place many group members displayed virtual acts of affection.

After coding was completed it was concluded that there was considerable overlap between the sub-categories ‘validation’ and ‘empathy’. They were therefore re-coded under the ‘Emotional Support’ category as ‘validation/empathy’. Furthermore, it was also evident that a new sub-category indicating the community’s unique position to share experiences existed. Therefore, we added this sub-category to the Esteem Support category as ‘Anchorage’. In addition, the ‘relief of blame’ sub-category was considered to represent emotional support as opposed to esteem support. Finally, the ‘express willingness’ sub-category was coded as network support as these messages reflected a general willingness to help by members of the group rather than a specific tangible act. Each message was coded by two raters and reliability was calculated based on the 5 main categories. Our analysis revealed good reliability with Cohen’s Kappa ranging from .86 to .94.

3. Results

Table 1 reports the frequency with which each of the five main categories and 22 subcategories were recorded. As can be seen, the most frequently recorded categories were informational and emotional support followed by network support with esteem support and tangible assistance being the least frequently offered.

<< Insert Table 1 about here >>

Information support

Messages within the advice category frequently offered guidance for coping with the challenges of HD, particularly in relation to decision-making. For example, one posting offered the following advice: “*the first thing you need to do is read, get informed so that you can make a decision*”. Referrals to experts often

included directing an individual to a specific organisation, textbook or website. Situation appraisals typically helped individuals to reassess or redefine their current experiences in a way that often helped individuals to identify a positive dimension to their struggle with HD. For example, one message proposed that *"if you are fortunate in the midst of this hard disease you will find a way to make this struggle make you a better person than you were when you started"*. Teaching included comments that provided factual or technical information about various aspects of HD, notably the genetic element of the disease.

Esteem support

Compliments offered praise for the individual and noted their abilities or attributes when facing such stressful experiences. For example, *"I admire you for being so useful and active during stressful times"* was posted by one group member. Messages providing anchorage noted the unique position of the community to share experiences of HD. For example, *"You can share anything you want with us on this long journey together. You are not travelling alone; you can share your experiences of this cruel disease. Here is a place where you say what you want about Huntington's. You will not be judged here"*

Network support

This category dealt only with structural connections, as emotional connections are classified elsewhere (i.e. emotional support). Any referrals to professionals were coded as informational support. Access messages invited individuals to participate in discussions or group activities. For example, one member posted *"Please come here anytime and tell us what you're feeling"*. Presence messages reminded group members that there is an existing network offering support and that there is always someone there for them. The 'companions' category reminded group members of supportive others. The final category of willingness to help often included comments such as *"I'd be happy to help anyway I can"*.

Emotional support

Emotional support included all efforts by the message sender to express empathy, support the emotional expressions of the recipient, or reciprocate emotion. Relationship support noted the importance of love and friendship and was typified by the posting *"My wife and I wish you all the love in the world"*. Virtual affection was represented textually, for example *"Big hugs to you"* or through the use of emoticons¹. Others expressed support through confidentiality such as *"I promise not to tell anyone, this is between you and I"*. Sympathy was communicated through postings such as *"I am so sorry to hear of your loss"*. The category of validation and empathy contained messages noting the similarity of experiences with others in the group. For example, *"I know! I have just been told and I was shocked and upset"*. Group members offered encouragement to each other, for example, *"I know you can do it"*. Prayer messages were offered to individuals who were suffering or in need of help, *"You and your family are in my thoughts and prayers"*. The last category, relief of blame, was the apparent objective of postings such as *"You shouldn't blame yourself...it's not your fault"*.

Tangible Assistance

This category of support reflected concrete, physical action in support of the recipient. The direct task category included postings to perform an action in response to a need or request. For example, *"Perhaps if you email me I can provide the nearest chapter for support"*. Active participation was illustrated by the posting *"I'd love to join you one day at this event"*.

¹ Smileys and other character art used to express feelings and emotions within computer-mediated communication systems.

4. Discussion and conclusion

4.1 Discussion

Our analysis of the online communication on this bulletin board indicates that it was used by members to exchange various types of social support. In particular, informational and emotional support were the most frequently provided, and appeared to be linked to the unique challenges faced by individuals who are affected by HD. The prevalence of both these categories of support within the present data is consistent with content analyses of bulletin boards for other chronic conditions [4,33,34]. In addition, it mirrors findings from the literature on face-to-face self-help groups [35].

Informational support appeared to be particularly beneficial to those individuals contemplating, undergoing or affected by the process of genetic testing. Moreover, approximately one fifth of messages posted offered highly technical or factual information about HD, notably the genetic element of the disease. The frequency with which such discussions took place was striking and it clearly signals the need for careful review and assessment of the quality of information provided. Indeed, previous research has shown that accounts from pre-symptomatic candidates for genetic testing illustrated a number of lay beliefs of risk perception, such as the gene skipping a generation and gender specificity [36]. If these lay perceptions were to be posted on the online board, there is potentially no limit to the number of individuals who could access them. Thus future research may usefully explore the validity of factual information, including corrections by members to any misperceptions of the facts regarding HD. Beyond this, informational support also served to provide advice (e.g. ways of coping) to members who were attempting to deal with the diverse and unique challenges of HD.

Providing emotional support to others also appeared to be an important function of the group with members typically acknowledging the feelings of others and validating them by reiterating their own similar views and experiences. This

category of support appeared to be particularly helpful to members (e.g. HD individuals, close family and loved ones) of the group who were directly affected by a positive result and were struggling to come to terms with the devastating impact of HD. Emotional support was also clearly in evidence for individuals who were trying to decide whether or not to have the genetic test. Although this decision can have major consequences for both the individual and others around them, the large number of postings under this category does appear to show that individuals are able to openly discuss these issues within an online support group environment. Recent research has shown that within groups of 'at risk' individuals (those who decide to get tested/not get tested) poorer adjustment is related to lower levels of social support and seeking social support coping [37]. It has also been identified that as HD is a rare condition, family members and patients often feel that they are betraying each other if they speak openly about their experiences [38]. Therefore, the online environment may facilitate social support by providing an anonymous environment through which individuals can disclose information that they would find difficult to articulate in a face-to-face context.

Network support appeared to be helpful to members from the perspective of providing a common 'meeting place' in which all manner of issues relating to HD could be discussed. Participants often reinforced the availability of support, particularly to new members. This is perhaps not too surprising given that a stated aim of the support group was to put people in touch with others who are also affected by HD. However, after initial reinforcement of such support had been made to new members, this theme typically became less salient within the messages posted. One possible explanation for this may be that the need for this type of support was addressed simply by participating in the bulletin board and that members did not necessarily need to make network support the focus of their message. As such, it would appear from this data that emotional and informational support needs may have been more salient to the participant than

network support *per se*, and thus required more explicit discussion within the board.

The primary function of esteem support offered by participants appeared to be validating the views of others and suggests that the members of this support network were in a unique position to offer comment on the range of emotional reactions to HD, which are experienced. The least frequently offered support was that of tangible assistance. Whilst the opportunities for this type of support may have been limited as a result of the mode of communication, there were nevertheless some observable examples of this type of support.

A number of important measures were taken throughout the research process in order to ensure that the findings presented are as reliable as possible. In particular, issues of credibility, dependability and transferability were considered to be key features of this process [39]. Credibility refers to the focus of the research and the extent to which confidence is placed in the processes underpinning the data analysis and the focus of the research. Within the present study, a number of important decisions were taken to ensure credibility. First, we decided to retrieve data from a large quantity of messages (approximately 1300) posted over 21 months by 793 individuals. Second, the use of a comprehensive coding system ensured that the analysis was undertaken within the context of an overall theoretical framework. The adapted Social Support Behaviour Code also provided a means of ensuring that content categories were well defined and explicit, such that all messages were coded by a second researcher yielding a high level of agreement. In addition, this ensured that our results were reliable and that there were no major changes over the duration of the analysis in how postings were being coded and text categorised. Finally, our analysis also allowed for some insight into the profile of participants with respect to their relationship to HD. This is important in helping determine the extent to which our results are transferable to other online bulletin boards and groups.

There are, however, a number of potential limitations to the present study, which must be taken into consideration. Firstly, we analysed messages posted to a single online support group for individuals affected by HD. The extent to which the observed pattern of social support is generalisable to other online groups has yet to be tested. Future research should seek to explore the categories of support provided across multiple online support groups. Secondly, the emphasis of this study was on the examination of the provision of social support in posted messages. It remains to be seen whether such messages were interpreted as being supportive in the manner intended, or indeed in accordance with the broad categories identified in this analysis. Future research may usefully encompass recipient interpretations as an additional source of data.

Despite these limitations, the methodology employed provides a unique opportunity to examine how individuals affected by HD engage in supportive communications. By using a methodology which retains message content and sequencing, there now exists a viable alternative to retrospective self-reports or researcher-developed scenarios.

4.2 Conclusion

The present study demonstrates that through an online Internet support group, individuals affected by HD may have new opportunities for information retrieval and social support. The results suggest that exchanging informational and emotional support represents a key function of this online group and appears to be linked to the unique challenges faced by individuals who are affected by HD. Future research should explore the categories of support across multiple online support groups, in order to establish the generalisability of these results. In addition, it may be useful to explore the accuracy of information exchanged regarding HD (and the genetic nature of the disease in particular) and encompass recipient interpretations as an additional source of data.

4.3 Practice implications

Online support groups provide a unique opportunity for health professionals to learn about the experiences and views of individuals affected by HD and explore where and why gaps may exist between evidence-based medicine and consumer behaviour and expectations. Undertaking this type of research may reveal a range of valuable data which may be useful in informing priorities for research, health communication and patient care.

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Table 1 Number and percentage of postings in each social support category

Support Category	No. of postings	% of total postings*
Information	730	56.2
Advice	538	41.4
Referral to experts	279	21.5
Situation appraisal	103	7.9
Teaching	253	19.5
Esteem	282	21.7
Compliment	115	8.9
Anchorage	167	12.9
Network	629	48.4
Access	524	40.3
Presence	153	11.8
Companionship	60	4.6
Express willingness	192	14.8
Emotional	674	51.9
Relationship	51	3.9
Virtual affection**	30	2.3
Confidentiality	92	7.1
Sympathy	117	9.0
Validation/empathy	363	27.9
Encouragement	392	30.2
Prayer	187	14.4
Relief of blame	38	2.9
Tangible assistance	127	9.8
Loan	0	0
Perform direct task	85	6.5
Perform indirect task	0	0
Active participation	48	3.7

* Expressed as a percentage of postings which contain social support (N=1299)

** Modified from physical affection