E-Health

An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication

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1. Introduction

1.1. Online support groups (OSGs)

It was reported in 2005 that an estimated 36 million Americans were members of online support groups [OSGs] [2]. While social support has long been acknowledged to have a positive effect on chronic illness sufferers [3,4], this rise in the use of OSGs can also be seen as symptomatic of people's changing attitudes towards their health. The increasing availability of health information through all media sources [5] and the increasing role of patient self-management in chronic illness [6,7] both act to encourage people to take a more active role in their health management.

Previous researchers have reported that OSGs are attractive alternatives to face-to-face support groups due to unique factors such as 24-h access, anonymity and asynchronicity, together with the ability to connect with a diverse community in terms of viewpoints [8], ethnicity [9], geography and social status [10–13].

However, there are disadvantages of OSGs, anonymity and lack of strong ties can make flaming or hostile comments more likely [8], lack of non-verbal communication means that messages can easily be misinterpreted [13] and there are also concerns about the accuracy of information shared [11]. However, in a study specifically investigating potential disadvantages in breast cancer, fibromyalgia and arthritis OSGs van Uden-Kraan et al. [14] found that on average questions were answered within 24 h, there were very few hostile messages and the medical information provided was accurate, concluding that OSGs were a viable medium for support.

This evidence creates a reasonably clear picture of the potential advantages and disadvantages, content and patient motivation for using OSGs. However, outcome studies have proved more equivocal [15]. Eysenbach et al. [15] concluded that while there was no evidence of any harm being done by OSGs, there was also no strong evidence of efficacy. However, many of the studies involved complex multi-faceted interventions and had methodological problems or focussed on specific illness factors. The studies that have found evidence of efficacy looked at factors such as improved emotional quality of life [16], hope [17] and negative reactions to pain [18], suggesting that OSGs improve general well-being patient factors rather than clinically significant illness factors [1,19].

The emotional and informational support provided through OSGs has been seen to improve a patient's perception of their social

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ABSTRACT

Objective: The current research investigates the potential of online support groups (OSGs) to foster empowerment and how membership might affect the patient/health professional relationship.

Methods: 246 participants across 33 OSGs completed an online questionnaire.

Results: All empowerment processes and outcomes identified by van Uden-Kraan et al. [1] were found to be present. All empowerment outcomes were adequately predicted by empowerment processes. The majority (82.2%) of participants had discussed information found online with their health professional and most (74.2%) were satisfied with the response. Around 60% of participants felt membership of an OSG had affected the relationship with their health professional and from qualitative responses the effects were mostly positive.

Conclusion: OSGs have the potential to produce empowerment outcomes for those who choose to use them. Furthermore, users report a positive reaction to information found online from their health professionals.

Practice implications: Although not all patients will benefit from using OSGs, health professionals suggesting their use could ensure that they reach the maximum receptive audience. Furthermore, this research could be used to encourage a more ‘net friendly’ attitude amongst health professionals.

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support and mirror the type of support gained from face-to-face support groups [20] but these increases in social support do not always confer health benefits [15]. It has been suggested therefore that an increase in perceived social support is just one of many empowerment processes [1,12,19], and this empowerment improves general well-being factors and can lead to more effective health service utilisation [19]. Empowerment is still a poorly defined concept within the literature [1], some authors suggesting that the idea of an empowered patient within a traditional medical paradigm is a paradox as it suggests independence and compliance simultaneously [21]. Others, however, view the empowered/informed patient as part of a more productive partnership with their health professional [22] leading to increased satisfaction and better health outcomes [23].

1.2. Empowerment and communication with health professionals

Empowerment through increased information leading to patients taking a more active role in consultations and health decision making and moving away from the traditional asymmetric power balance inherent in the medical model [21], has been identified as key by the UK Department of Health [24]. The internet is seen as having the potential to facilitate this, through the provision of emotional support needed to make an appointment [12], the informational support to prepare for a consultation [10] and playing a key mediating role between health professional and patient during the consultation [22,25].

In this ‘increasing triangulation’ of the internet, patient and health professional [22, p. 221] to ensure patient satisfaction it is important that there is congruency between the amount of information desired by the patient and the amount given by the health professional [26]. In 2007, 75% of primary care trust physicians reported that patients had come to them with information found online [22]. Therefore, in order to maximise the potential benefits of empowerment for those patients that desire a more active role in health decision making it has been proposed that health professionals must become more ‘net friendly’ [23, p. 1148]. The reaction a patient gets to information they bring can be critical to the level of satisfaction a patient feels [27]. The ability to share information and feel valued by their health professional is important for those patients wishing to take a more active role [28] but the positive effects of empowerment on patient well-being and better health service utilisation are dependant firstly on the health professional’s reaction to information [6,27–29] but also the patient’s perceptions of their potential reaction [30]. This research aims to investigate perceptions of OSG users of both empowerment and communication with their health professionals.

1.3. Aims

This study aims to answer the following questions: What empowerment processes/outcomes are present when using OSGs? Do OSG users feel comfortable taking information to a healthcare professional, and what are their experiences of this? And is there a connection between empowerment and sharing internet information with a health professional?

2. Method

2.1. Participants

A total of 246 individuals were recruited from 33 chronic illness online support groups. The sample consisted of 72 males (29.3%) and 174 females (70.7%) aged 21–100 (mean = 50.41). Length of membership ranged from less than a week to 725 weeks (nearly 14 years) with a mean of 143.61 weeks (approximately 2.8 years). The exact number of support groups that posted the questionnaire is difficult to ascertain, of the 158 support groups emailed 32 moderators responded positively and one group was identified as having posted through an email from a member. This leaves the possibility that further moderators did post the link but did not confirm this. The majority of groups focussed on arthritis, diabetes or cancer although a wider range of chronic illnesses were included.

2.2. Materials

The questionnaire consisted of three sections, the first collected demographic and descriptive information of how long participants had used the specific OSG and whether the internet was used in other health related ways (i.e. searching for key terms). The second section used questions from van Uden-Kraan et al. [31], and aimed to identify how often empowering processes were encountered within OSGs, and how often empowering outcomes were felt to have occurred as a result of OSG participation. The final section of the questionnaire asked about participants’ relationship with their health professional and whether being a member of an OSG was perceived to have affected this [28].

2.3. Procedure

Online support groups were identified by searching for terms ‘online support group’, ‘cancer support group’, ‘arthritis support group’ and ‘diabetes support group’ on Google. Multi-illness sites were also emailed, for example chronic illness support groups on About.com and Yahoo Groups. Further groups were identified throughout the study from further searching and participant suggestion. Groups were emailed if their primary aim was to provide support for patients with a chronic physical illness. Groups focussing solely on mental illness were not included as it was felt there would be potential for serious mental health problems to confound empowering effects. The aim of this study was to test van Uden-Kraan et al.’s findings with a more diverse group of physical illnesses. Groups were also excluded if their aim was to provide solely information, or to promote a certain point of view; if they were aimed at paediatric populations/careers/friends or relatives, if they had fewer than 5 members or were inactive in the past month. Moderator/Owner email addresses were sought and emailed. Groups that required membership before obtaining the moderator’s email address were discounted.

A suggested forum post was provided containing key information about the study, some moderators used this and others wrote their own posts. All the key information was repeated on the first page of the questionnaire to ensure all participants saw this.

2.4. Analysis

Multiple items on the questionnaire were averaged to create single variables for each empowerment process and outcome. The data was then explored using descriptive statistics, frequencies and correlations and analysed with both multiple and binary logistic regressions.

3. Results

The results were downloaded and participants who had consented to take part but failed to answer any further questions were removed. IP addresses were checked for duplication.

3.1. Empowerment processes and outcomes

The results showed that the most common empowerment process found in OSGs was comparison with other support group
members, 67.1% (N = 165) of participants experienced this either regularly or often, 65.9% (N = 162) reported helping others as being present; 64.6% (N = 159) experienced sharing information; 63.8% (N = 157) reported sharing experiences and 30.9% (N = 76) reported experiencing social support either regularly or often. The most commonly found empowerment outcome was feeling better informed (79.3%, N = 195) followed by enhanced social well-being (52%, N = 128), improved confidence in their treatment (51.6%, N = 127), enhanced self-esteem (44.3%, N = 109), feeling more confident in the relationship with their physician (37%, N = 91), improved acceptance of their illness (27.2%, N = 67) with the least commonly found being increased optimism and control over the future (19.1%, N = 47).

Correlations between empowerment processes and outcomes were investigated (see Table 1) all processes were significantly correlated to all outcomes with the exception of the information exchange process.

Multiple regressions were performed using the Enter method to ascertain which processes explained the greatest amount of variance in each outcome. Due to the high level of initial correlation multicollinearity was investigated, and no corrections were necessary.

The variables entered significantly predicted each of the empowerment outcomes (see Table 2). Enhanced social well-being was predicted by two variables explaining 30.7% of the variance (adjusted $R^2 = 0.307, F(7,237) = 16.459, p < 0.001$). Increased confidence in their physician was predicted by two processes explaining 30.5% of the variance (adjusted $R^2 = 0.305, F(7,237) = 16.330, p < 0.001$). Feeling more informed was significantly predicted by two processes explaining 30% of the variance (adjusted $R^2 = 0.3, F(7,237) = 15.962, p < 0.001$). Increased confidence in the treatment and increased acceptance of the illness were both predicted by two variables explaining 25.6% and 23.1% of the variance respectively (adjusted $R^2 = 0.256, F(7,237) = 12.972, p < 0.001$ and adjusted $R^2 = 0.231, F(7,237) = 11.449, p < 0.001$). And finally, enhanced self-esteem and increased optimism and hope for the future had only one significant predictor each explaining 18.7% and 15.8% of the variance respectively (adjusted $R^2 = 0.187, F(7,237) = 8.994, p < 0.001$ and adjusted $R^2 = 0.158, F(7,237) = 7.557, p < 0.001$).

The most commonly found predictor was comparison with other members (predicting 5 out of the 7 outcomes) while sharing experiences and exchanging information did not reach significance for any of the outcomes. The majority of participants (93.5%, N = 230) used the internet to gain health information in ways other than OSGs, such as searching for key terms.

### 3.2. Influence of OSG membership on relationship with the health professional

It was found that 82.2% (N = 199) of participants had discussed information they had found on the internet with their health professional, 74.2% (N = 147) of these had reported being either satisfied or extremely satisfied with their health professional’s reaction, only 16.2% (N = 33) reported either being dissatisfied or extremely dissatisfied. The explanations given by those who did not share information with their health professional are given in Table 3.

A binary logistic regression was performed to investigate whether empowerment processes or outcomes could predict whether OSG users felt comfortable taking information found online to their health professionals. The model included all empowerment processes and outcomes as well as age, gender and length of membership as possible predictors and significantly predicted discussion of online information with a health professional (omnibus Chi-square = 53.048, df = 15, $p < 0.001$).
explained between 19.8% and 32.5% of the variance in discussion status and predicted 99% of those people who did discuss information compared with 34.9% of those who did not. Overall 87.6% of the predictions were accurate. The two variables that significantly predicted discussion of information were the empowerment process exchanging social support and the length of membership variable (see Table 4). The negative coefficients indicate that as exchange of social support and length of membership increase the likelihood of participants discussing online information with their health professional decreases.

In order to investigate further how using an OSG could affect the health professional/patient relationship participants were asked ‘do you think being a member of an internet support group has altered your relationship with your health professional?’ 60.3% \((N = 144)\) of participants felt it had, 39.7% \((N = 95)\) felt it had not. A further binary logistic regression was performed to investigate whether the presence of empowerment processes or outcomes predicted whether participants would feel the relationship with their health professional had changed. Including all the empowerment processes and outcomes together with age, gender and length of membership in the model resulted in being able to correctly predict 73.9% of cases overall (86% of those who answered yes, 55.8% of those who answered no). This is a significant prediction \((\text{omnibus chi-square } = 74.376, \text{df } = 15, \text{ } \text{ } p < 0.001)\) explaining between 26.8% and 36.3% of the variance.

The three factors that had a significant role in predicting whether participants felt their relationship with their health professional had changed were improved confidence in their

### Table 2

**Significant predictors of empowerment outcomes.**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Significant predictors</th>
<th>B</th>
<th>SE</th>
<th>(\beta)</th>
<th>Total % variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling more informed</td>
<td>Comparison with other members</td>
<td>0.434</td>
<td>0.086</td>
<td>0.366**</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>Helping others</td>
<td>0.190</td>
<td>0.096</td>
<td>0.186**</td>
<td></td>
</tr>
<tr>
<td>Increased confidence with physician</td>
<td>Comparison with other members</td>
<td>0.360</td>
<td>0.070</td>
<td>0.372**</td>
<td>30.5%</td>
</tr>
<tr>
<td></td>
<td>Helping others</td>
<td>0.207</td>
<td>0.078</td>
<td>0.247**</td>
<td></td>
</tr>
<tr>
<td>Increased acceptance of illness</td>
<td>Comparison with other members</td>
<td>0.253</td>
<td>0.078</td>
<td>0.247**</td>
<td>23.1%</td>
</tr>
<tr>
<td></td>
<td>Exchanging social support</td>
<td>0.172</td>
<td>0.086</td>
<td>0.161</td>
<td></td>
</tr>
<tr>
<td>Increased confidence in treatment</td>
<td>Comparison with other members</td>
<td>0.313</td>
<td>0.076</td>
<td>0.310**</td>
<td>25.6%</td>
</tr>
<tr>
<td></td>
<td>Length of membership</td>
<td>0.001</td>
<td>0.001</td>
<td>0.117**</td>
<td></td>
</tr>
<tr>
<td>Increased optimism and hope for the future</td>
<td>Comparison with other support group members</td>
<td>0.148</td>
<td>0.061</td>
<td>0.195**</td>
<td>15.8%</td>
</tr>
<tr>
<td>Enhanced self-esteem</td>
<td>Exchanging social support</td>
<td>0.312</td>
<td>0.101</td>
<td>0.255**</td>
<td>18.7%</td>
</tr>
<tr>
<td>Enhanced social well-being</td>
<td>Exchanging social support</td>
<td>0.512</td>
<td>0.101</td>
<td>0.384**</td>
<td>30.7%</td>
</tr>
<tr>
<td></td>
<td>Length of membership</td>
<td>0.001</td>
<td>0.001</td>
<td>0.142**</td>
<td></td>
</tr>
</tbody>
</table>

\* Significance at \(p < 0.05\).

\** Significance at \(p < 0.01\).

### Table 3

**Reasons given for not sharing online information with a health professional, categorised according to Imes et al. [28].**

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information attribution</td>
<td>63</td>
</tr>
<tr>
<td>Systems and circumstance</td>
<td>15</td>
</tr>
<tr>
<td>Turf issues</td>
<td>7</td>
</tr>
<tr>
<td>Face-saving reasons</td>
<td>3</td>
</tr>
<tr>
<td>Indirect references</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
</tr>
</tbody>
</table>

### Table 4

**Coefficients, Wald statistics and probability of all predicting factors of discussion of information found online with a health professional.**

<table>
<thead>
<tr>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>df</th>
<th>Probability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.014</td>
<td>0.017</td>
<td>0.677</td>
<td>1</td>
</tr>
<tr>
<td>Gender</td>
<td>0.071</td>
<td>0.432</td>
<td>0.027</td>
<td>1</td>
</tr>
<tr>
<td>Length of membership</td>
<td>-0.006</td>
<td>0.002</td>
<td>7.041**</td>
<td>1</td>
</tr>
</tbody>
</table>

**Empowerment processes**

- Exchanging information: \(-0.353, 0.296, 1.426, 1\)
- Exchanging social support: \(-1.107, 0.404, 7.493**, 1\)
- Comparison with other members: \(-0.013, 0.340, 0.001, 1\)
- Helping others: \(0.216, 0.378, 0.326, 1\)
- Sharing experiences: \(0.259, 0.349, 0.550, 1\)

**Empowerment outcomes**

- Feeling informed: \(-0.605, 0.395, 2.350, 1\)
- Increased confidence with physician: \(-0.486, 0.588, 0.683, 1\)
- Increased acceptance: \(0.420, 0.401, 1.094, 1\)
- Increased confidence in the treatment: \(-0.111, 0.497, 0.049, 1\)
- Increased optimism and hope for the future: \(0.764, 0.654, 1.363, 1\)
- Enhanced self-esteem: \(-0.268, 0.347, 0.597, 1\)
- Enhanced social well-being: \(-0.188, 0.281, 0.446, 1\)

\** Significance at \(p < 0.01\).
relationship with their health professional, length of membership and age (see Table 5). The coefficients of these variables were negative, indicating that as age, length of membership and confidence in relationship with their physician increased, the odds of feeling that the relationship has been affected by OSG membership decreased.

### 4. Discussion and conclusions

#### 4.1. Empowerment processes and outcomes

The aims of the current research were to investigate which empowerment processes and outcomes were present and if and/or how they affected the doctor/patient relationship. The most commonly found empowerment outcome was feeling better informed. This finding suggests the important role played by information while using OSGs and supports previous findings that have identified informational support as the most commonly found form of support within OSGs [e.g., [10,12,32]]. The most commonly found empowerment process was comparison with other members although it is almost matched (within 5%) by the occurrence of helping others, sharing experiences and exchanging information. This indicates that these empowerment processes work together to impact on feeling more informed, a patient's well-being, and other empowerment outcomes [1,19].

Comparison with other OSG users was a significant predictor of five out of the seven empowerment outcomes. This finding supports the view that it is not only finding the information that serves to empower users, but also how it is presented [1,25]. Through comparison with other support group users the experiential nature of the information is highlighted [8]. The amount of variance explained by empowerment processes supports the view that OSGs can play a role in promoting empowerment outcomes [33].

The fact that all the processes and outcomes identified by van Uden-Kraan et al. [1] were found by between 19.1% and 79.3% of participants suggests that their findings can be generalised beyond fibromyalgia, breast cancer and arthritis into many other chronic conditions.

#### 4.2. The role of OSG membership in relationships with health professionals

Empowerment processes explained 30.5% of the variance in the outcome ‘feeling increased confidence in the relationship with their physician’ suggesting a strong role of OSGs in affecting the health professional/patient relationship [22]. Previous research has found mixed results regarding health professional’s reactions to online information [6] and patient perceptions of sharing this information [30]. These findings show the majority (82.2%) of participants had discussed information found online with their health professional and 74.2% were satisfied with the response. Furthermore, of those that had not discussed this information the most commonly identified reasons were information related, for example, they did not want to or felt it unnecessary rather than feeling they could not.

Our results showed that as length of membership and exchanging social support increase, the likelihood of sharing information with the health professional decreases, this together with the above evidence suggests that as time goes on participants may not feel the need to share information with their health professional, and that perhaps OSGs are used more for social support than decision making. Previous research has found evidence of optimal matching in the types of support offered, for example, informational support for treatment decisions and emotional support in times of stress [34]. It therefore follows that such optimal matching might occur in the differing roles OSGs play in empowerment, as the needs of this participant group change over time [35] the necessity to share information with the health professional could also be expected to fluctuate.

Although it is clear that the majority of participants felt comfortable taking information to their health professional, perceptions of whether being a member of an OSG affected the relationship with their health professional were more varied with around 60% of participants feeling that membership had altered their relationship. As age, length of membership and confidence with the physician increased, the odds of feeling that the relationship had been changed by OSG membership decreased. This could be due to the fact that older participants may have been diagnosed longer, possibly before OSGs were so prevalent so the benefits they may have for the newly diagnosed are not present in this group. As there is no baseline for this study it could be argued that participants felt their relationship was unchanged due to feeling confident before becoming members of OSGs. Furthermore, OSG use and relationship with the health professional is known to fluctuate over the course of the illness [29,34]. Older participants and long-term members may have already made all the key treatment decisions and now be in a phase of maintenance, therefore although they may receive general well-being improvements from OSGs the relationship with the health professional would be unaffected.

### Table 5

<table>
<thead>
<tr>
<th>Empowerment processes</th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>df</th>
<th>Probability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exchanging information</td>
<td>-0.126</td>
<td>0.248</td>
<td>0.259</td>
<td>1</td>
<td>0.607</td>
</tr>
<tr>
<td>Exchanging social support</td>
<td>-0.421</td>
<td>0.340</td>
<td>1.531</td>
<td>1</td>
<td>0.222</td>
</tr>
<tr>
<td>Comparison with members</td>
<td>-0.140</td>
<td>0.254</td>
<td>0.226</td>
<td>1</td>
<td>0.609</td>
</tr>
<tr>
<td>Helping others</td>
<td>0.133</td>
<td>0.184</td>
<td>0.175</td>
<td>1</td>
<td>0.680</td>
</tr>
<tr>
<td>Sharing experiences</td>
<td>0.019</td>
<td>0.298</td>
<td>0.004</td>
<td>1</td>
<td>0.999</td>
</tr>
<tr>
<td>Empowerment outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling informed</td>
<td>-0.519</td>
<td>0.354</td>
<td>2.145</td>
<td>1</td>
<td>0.146</td>
</tr>
<tr>
<td>Increased confidence with physician</td>
<td>-1.372</td>
<td>0.474</td>
<td>8.368*</td>
<td>1</td>
<td>0.004</td>
</tr>
<tr>
<td>Increased acceptance</td>
<td>0.467</td>
<td>0.314</td>
<td>2.213</td>
<td>1</td>
<td>0.139</td>
</tr>
<tr>
<td>Increased confidence in treatment</td>
<td>-0.023</td>
<td>0.403</td>
<td>0.003</td>
<td>1</td>
<td>0.951</td>
</tr>
<tr>
<td>Increased optimism and hope for the future</td>
<td>-0.183</td>
<td>0.478</td>
<td>0.146</td>
<td>1</td>
<td>0.833</td>
</tr>
<tr>
<td>Enhanced self-esteem</td>
<td>0.039</td>
<td>0.288</td>
<td>0.018</td>
<td>1</td>
<td>0.903</td>
</tr>
<tr>
<td>Enhanced social well-being</td>
<td>0.090</td>
<td>0.238</td>
<td>0.144</td>
<td>1</td>
<td>0.706</td>
</tr>
</tbody>
</table>

* Significance at p < 0.05.
** Significance at p < 0.01.
Again, these results suggest a changing role of empowerment through OSGs depending on the members’ situation.

For those that did feel the relationship had been affected many of the qualitative answers focused on the idea that from using the group patients felt better prepared for consultations, they knew what questions to ask and felt more informed about symptoms, treatments and their illness. This suggests that although the question was open ended the majority of participants if they reported an effect, reported a positive one. Further qualitative research would be needed to investigate the details of this effect further.

4.3. Limitations and future directions

This sample consisted wholly of existing OSG members, meaning the results should not be generalised beyond this group. The wide range of chronic illness OSGs included could suggest applicability within this group might be possible but as Rogers & Mead discuss not everyone will experience empowerment effects over the internet [30] and those that do not feel any benefits are unlikely to become or remain members of OSGs, and would therefore not be represented in this sample. This might have inflated the findings concerning discussing online information with the health professional, as this sample might be more confident in this by nature.

Perhaps questions regarding health professionals should also include a more detailed description of whom the participant is referring to as in the case of most chronic illnesses there is not a singular health doctor/patient relationship but rather a relationship with a team of multidisciplinary specialists. Wilson et al. [6] found that how receptive a health professional was differed according to position. This study was cross-sectional so no causality can be assumed meaning OSG membership could be the result of empowerment rather than a contributing factor. It has been found that some patients discover OSGs following searching for key terms about their illness [12] indicating an existing desire to search for information and improve empowerment. Although feeling more informed was the most commonly found empowerment outcome, information exchange as a process within OSGs did not significantly predict any outcomes. As the vast majority (93.5%) of participants used the internet in other health related ways, it becomes difficult to ascertain the unique influence of OSG membership. Furthermore, there was no measure of change over time. The results found indicate an important role for length of membership in predicting health professional/patient relationship factors but these results were taken at one timepoint. As previously mentioned, relationships with OSGs have been found to change over time [34,35] and information might be needed more in the initial stages of illness when a larger number of decisions need to be made rather than a continuation of care when perhaps more emotional support would be valued [4]. In this study it would not have been possible to ask about stages of illness, or weeks since diagnosis as there were such a wide range of illnesses included. The diversity in the chronic conditions studied may have also affected the results in itself as the needs of this diverse group of participants could be expected to differ substantially [35]. No information regarding co-morbid conditions was collected in this study and it could be expected that a proportion of the participants may have been experiencing depression/anxiety or other mental health problems as well as concurrent physical illnesses. It would be interesting in future research to investigate how these factors effect empowerment in OSG users.

4.4. Conclusions

Online support group membership may enable participants to experience empowerment processes and achieve empowerment outcomes as proposed by van Uden-Kraan et al. [1]. This study has shown these to occur over a wider range of chronic illnesses. Empowerment processes were found to predict empowerment outcomes supporting the role of OSGs as possible contributors to patient empowerment. The majority of participants were found to have shared information found online with their health professionals and been satisfied with the response. Over half the participants felt that membership of an OSG had affected their relationship with their health professional, the qualitative data suggesting that this change was positive.

4.5. Practice implications

These findings support the view that OSGs can be used by certain patients of chronic illness to foster empowerment, although the exact role the OSG plays may change over time. It could therefore be suggested that health professionals should introduce OSG naive patients to the idea of OSGs as part of a more patient centred approach.

References


