

A Review of Opportunities and Challenges of Carers' Support on Online Social Platforms

Completed Research Paper

Bavya Mukundan

Faculty of Engineering & IT, University of
Technology Sydney
Ultimo, Sydney, Australia
Bavyamukundan@student.uts.edu.au

Babak Abedin

Faculty of Engineering & IT, University of
Technology Sydney
Ultimo, Sydney, Australia
Babak.Abedin@uts.edu.au

Abstract

The purpose of this study is to investigate opportunities and challenges of carers' support on online social platforms. We conducted a systematic literature review of 20 journal articles, and explored positive and negative aspects of online social platforms in three main categories: (i) Carer Wellbeing, (ii) Care Service, and (iii) Common Opportunities or Challenges. A Demographic analysis of publication year, country, user type, and research method have been discussed. The study uncovered that online platforms have a proportional amount of positive and negative impacts. We found that (i) the challenges guide us on how to educate carers and plan for uncertainties, and (ii) the opportunities shed a ray of hope on ways to assist the carers using online social networks. Results guide future research in mitigating challenges and strengthening opportunities for supporting and empowering carers on online social platforms.

Keywords: Carers, Caregivers, Online Social Platforms, Opportunities, Challenges

Introduction

For years, many studies have been conducted to enhance the life of patients. While patients go through many discomforts, consequently, their carers, who provide that selfless care to family members or friends, undergo a rollercoaster ride of emotions and distress of their own. Online social platforms have proved to be able to facilitate exchange of social health support for patients (Erfani et al., 2017; Erfani et al., 2016). However, research on carers support on the Internet (Nolan & Dellasega 2000), and particularly through online social networks has been low scale.

The need to take care of patients do not end in hospitals, but its obligation extends to homes as well. According to a study done by Tsigaropoulos et al. (2009), the significant problems faced by carers are due to the worry regarding the patients' future, financial burden, travel demands, grief, insufficient support from relative, complicated nature of the patient and much more. Unfortunately, many of the above trouble go unnoticed or undetected (Tsigaropoulos et al. 2009). Having said that, the difficulties of carers are not small scale. For instance, the intensive care (ICU) survivors are taken care usually by their family members once they return from the hospital. These carers have gone on record stating that they undergo immense burden while taking care of their relative. Apart from the sense of difficulty, these carers face enormous mental and physical pain. Their caring role is highly demanding, and it adversely affects the carer's health and well-being. According to some statistics, 58% of the carers experience severe deterioration in wellbeing once they undertake the care service, and yet many family members take up this role due to their emotional connection with the patient (Foster & Chaboye 2003).

Online social networks have great potentials in assisting individuals as well as organizations to build and sustain social relationship between network members (Abedin, 2016). In the context of health support, there have been several studies on how social support on online social platforms can try combating the above issues and impact users' wellbeing (Erfani et al., 2017; Erfani et al., 2016; Foster & Chaboye 2003). Carers feel that they can enhance their confidence when they are provided abundant information when required, and even can improve their skills by attaining quality professional training or support online. It is imperative for both the patients and supporting carers in achieving all vital information in the initial stages to cope with the sudden change in lifestyle. Many carers lack the confidence to take up many nursing tasks at home since they do not have the core information on the job to be implemented (Bee, Barnes & Luker 2009). Apart from emotional support, carers also require financial stability since taking care of the patient demands a hefty amount of cash. Moreover, the family members/carers are expected to work harder and juggle between work and home (Perkins & LaMartin 2012). According to Breskovic, De Carvalho, Schinking and Tellioglu (2013) carers also need more social inclusion, sense of security, active lifestyle, and improved wellbeing. Perkins & LaMartin (2012) has noted that online services have a promising future in helping carers and opposing the issues as mentioned above.

As suggested by Perkins & LaMartin (2012), there is immense chance to study on the utilization of various online social platforms for the betterment of carers. This paper, as part of a larger study, therefore aims to explore positives and negatives of using the online social platforms for supporting carers, hence providing a broader perspective on how one can use the positives to make better use of online platforms and on the contrary, being aware of the negatives help in becoming cautious. After a review of the literature, we will outline the methodology we used for conducting a systematic review of journals used in this project. Subsequently, the resultant framework portraying both the bright and dark side of online platforms followed by a discussion is available in the segment after the research method section. The result portion also depicts a comparative demographic study based on article year, user type, country, and research methods. Ultimately, we discuss our future research direction as well as the potential for future research opportunities.

Literature Review

The carers implement many crucial varied tasks at once hence to ensure the efficiency of care service it is essential to keep a check on the quality levels continuously (Maiden et al. 2013). Just like the patients, the caregivers go through various levels of emotions from the time the patient gets diagnosed and the journey afterward (Namkoong et al. 2012). After a few months of being diagnosed, both the patient and the carers normally experience an extreme state of distress, low satisfaction of life and hopelessness (Janda et al. 2017). There is a high change in the standard lifestyle of carers after the member takes up the caregiving role. That reform could lead new problems in return. Besides, due to social isolation, they face physical and social hurdles, which can make acquiring of information a difficult task. Eventually, carers undergo a phase of emotional, physical and social challenges (Namkoong et al. 2012). The drawback of not receiving vital information and support when required is that carers resort to a 'trial and error' procedure to ease any discomfort (Bee, Barnes & Luker 2009). A significant demand from a section of carers is the need for relevant information, which would be accessible and help in enhancing the essence of the care service. Conversely, there are family members/caregivers who do not consider the caring duty a burden instead they are delighted as it assures them a feeling of accomplishment and those moments of togetherness help in bringing more attachment between them (Greenwood et al. 2009).

Many types of solutions have been implemented in the past to challenge issues such as strain and depression. One of the solutions was the educational and training programs (Hu et al. 2014). However, Hu et al. (2014) noticed that carers find it difficult to attend these programs due to high care service demand. On the other hand, hi-tech facilities such as telephones, mobile phones, video phones, personal computers and the Internet came in to play to help carers. These services are more accessible to the caregivers (Hu et al. 2014). According to King et al. (2010), amongst all the solutions suggested, online social platforms have been the most efficient one since it is readily available, can connect people with clinical services and has high efficiency. Various types of online social platforms are available,

including tablet/mobile apps as well as social media websites where carers can store specific details and provide care better by being person-oriented (Maiden et al. 2013).

Namkoong et al. (2012) claim that the online assistance service named Interactive Cancer Communication Systems (ICCS) can improve the caregiver's mental well-being. Another tool, which enhances wellbeing and eases stress, is an Internet-based application (Hu et al. 2014) that is a home-based non-profit ICCS named CHESS. The latest version of CHESS concentrates on lung cancer and strives towards benefiting both patients and carers. In addition, CHESS forum board is a computer-mediated support system (CMSS) which allows users to interact anonymously hence ensuring privacy. The utilization of CMSS eliminates grief, improves health levels, and reduces strain. Through the online forum, carers get an incredible opportunity to interact with other people who are facing the same challenges. Moreover, through such interactions, users can attain a solid motivational, emotional, and knowledge-based support. People can explore problems that other fellow group members face and work together to find solutions and achieve relief. There is a substantial similarity between the elements in CMSS and the face-to-face human interaction. On the other hand, CMSS is different from informal settings such as Yahoo.com as it has a strict schedule, consists of both educational and group interaction elements and sealed membership subscription (Namkoong et al. 2012). Nevertheless, there is a group of carers who may not be satisfied by the use of online assistance. For instance, as stated by Perkins & LaMartin (2012) the older people find inconvenience in using computer or Internet services. Another issue, which broadly exists, is the ignorance of developers towards the users' level of literacy and readability on the online topics. Apart from age, the carers with low-income rates or origin from a minority ethnic group can be a hurdle in using the Internet. There are also worrying claims on social network sites concerning fake friendship, lack of privacy, a chance of nervousness and even online arguments. Moreover, there are transparency issues on whether specialists indeed run the health services on Facebook or not (Perkins & LaMartin 2012).

There are broadly two different sections of demands from the carers. On one side carers want to enhance the caregiving duty (Bee, Barnes & Luker 2009; Greenwood et al. 2009), whereas, others are in need of improved self-health levels (Greenwood et al. 2009; Hu et al. 2014; Janda et al. 2017; Maiden et al. 2013; Namkoong et al. 2012; Torp et al. 2013). The research work over the years has separately focused on the positives and negatives of the impact of online services on carers. Also, the research provides a solid understanding of different perspectives and expectations for the betterment of caregiver's lives. However, the downside is that examination of the advantages and disadvantages of technology separately does not provide any new direction or ray of hope to help carers efficiently. It implies that there is a need to conduct a collaborative study on both the bright and dark side of the implementation of online platforms by supporting carers. The systematic literature review in this study will help in critically analyzing impacts of online services on caregivers and ultimately provide a new direction in research. The further section discusses regarding the procedures deployed to execute the systematic review.

Research Method

We have executed a systematic literature review using the Abedin et al. (2013) and Abedini et al. (2017)'s guidelines. The systematic review has helped in rigorously segregating necessary information from the finalized set of research articles and conducting a critical analysis of the collected data. The collection of articles chosen for this study were scrutinized to ensure that their content is connected to the research objective which is to study the opportunities and challenges of supporting carer using online platforms.

The articles were fetched from the database 'Scopus' and the keywords applied were "Carer" AND "Internet" OR "Online." After which in stage 2 the four main inclusion criteria were applied as follows: 1. Only English language 2. Document type must be Article 3. The article must be older than the year 2000. 4. The article must be from the subject area of 'Computer Science' or 'Social Science'. In stage 3 filtration, the articles were analyzed based on its titles and abstract. Finally, the set of articles for the systematic literature review were shortlisted as shown in table 1, after the complete text was studied to

confirm it was relevant for the objective. Figure 1 illustrates the set of the procedures implemented in this study.

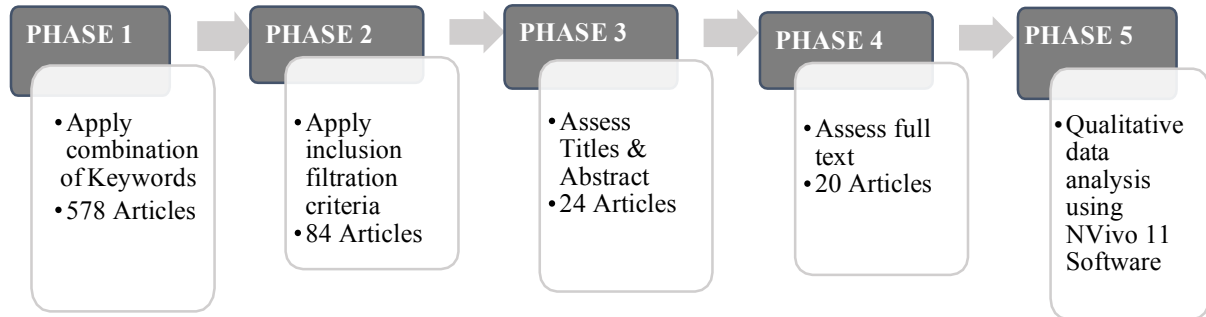


Figure 1: Systematic Literature Review Methodology

We used NVivo 11 Software to execute qualitative data analysis of the finalized 20 articles. Ultimately the methodology assisted in attaining pieces of evidence in regards to both plus and minus of Online Platforms for Supporting Carers. Eventually, the obtained shreds of evidence formed the resultant framework of this study.

Table 1. List of Articles

| Author | Title | Journal Name |
|--|---|---|
| (Boulos et al. 2015) | “LiveWell - Promoting healthy living and wellbeing for Parkinson patients through social network and ICT training: Lessons learnt and best practices” | International Journal of Healthcare Information Systems and Informatics |
| (Octoman & McLean 2014) | “ Challenging behaviour in foster care: what supports do foster carers want?” | Adoption and Fostering |
| (Subirats et al. 2013) | “Circles of Health: Towards an advanced social network about disabilities of neurological origin” | Journal of Biomedical Informatics |
| (Blusi,Asplund & Jong 2013) | “Older family carers in rural areas: Experiences from using caregiver support services based on Information and Communication Technology (ICT)” | European Journal of Ageing |
| (Dodsworth et al. 2013) | “Internet technology: An empowering or alienating tool for communication between foster-carers and social workers?” | British Journal of Social Work |
| (Loane & D'Alessandro 2013) | “Communication That Changes Lives: Social Support Within an Online Health Community for ALS” | Communication Quarterly |
| (Surman & Bath 2013) | “An assessment of the quality of information on stroke and speech and language difficulty web sites” | Journal of Information Science |
| (Hogden,Greenfield,Nugus & Kiernan 2013) | “What are the roles of carers in decision-making for amyotrophic lateral sclerosis multidisciplinary care?” | Patient Preference and Adherence |

| | | |
|-----------------------------------|--|--|
| (Gray & Robinson 2009) | “Hidden children: Perspectives of professionals on young carers of people with mental health problems” | Child Care in Practice |
| (Scott et al. 2017) | “ Using mobile devices for learning in clinical settings: A mixed-methods study of medical student, physician and patient perspectives ” | British Journal of Educational Technology |
| (Lucas 2015) | “ New technology and illness self-management: Potential relevance for resource-poor populations in Asia ” | Social Science and Medicine |
| (Yardley & Nyman 2007) | “Internet provision of tailored advice on falls prevention activities for older people: A randomized controlled evaluation” | Health Promotion International |
| (Mills 2006) | “When humans need humans: The lack of use of computer-based ICT in distance pastoral care” | Interacting with Computers |
| (Read & Blackburn 2005) | “Carers' perspectives on the internet: Implications for social and health care service provision” | British Journal of Social Work |
| (Blackburn,Read & Hughes 2005) | “Carers and the digital divide: Factors affecting Internet use among carers in the UK” | Health and Social Care in the Community |
| (Bath & Bouchier 2003) | “Development and application of a tool designed to evaluate web sites providing information on Alzheimer's disease” | Journal of Information Science |
| (Tann,Platts,Welch & Allen 2003) | “Patient power? Medical perspectives on patient use of the Internet” | Prometheus (United Kingdom) |
| (Timmons 2001) | “Use of the Internet by patients: Not a threat to nursing, but an opportunity?” | Nurse Education Today |
| (Perkins & LaMartin 2012) | “The Internet as Social Support for Older Carers of Adults With Intellectual Disabilities” | Journal of Policy and Practice in Intellectual Disabilities |
| (Sernani, Claudi & Dragoni 2015) | “ Combining Artificial Intelligence and NetMedicine for Ambient Assisted Living: A distributed BDI-based expert system ” | International Journal of E-Health and Medical Communications |

Result

After applying the keywords and inclusion criteria, a total of 84 articles were obtained. Next, the titles and abstract were rigorously studied. Ultimately, after assessing the full text, we selected 20 articles. Figure 2-5 portrays the demographic results of these studies.

Figure 2 illustrates the number of articles by the corresponding publication year. Significant internet-based innovations have been majorly after the year 2000. Most articles as shown in the figure were published in the year 2013. Figure 3 shows the comparative bar graph based on the user type and the number of articles. Clearly, amongst the various user types, Carer's of older people and children with a value two have been a significant focus amongst researchers in recent years. All other user types fall in the second position, each with a value of 1.

Figure 4 shows the count of articles published based on the countries/regions. 50% of the articles have been from U.K. Australia holds the second highest position with 18.75%. The other regions share an equal percentage of 6.25%. The authors of 20 articles employed a combination of different research methods. As represented in Figure 5 literature review, semi-structured interviews, and Web evaluation tools are the most occurring methodologies in this study. Other authors have utilized postal survey, online surveys, focus groups, telephonic interviews, Cross-sectional survey and much more.

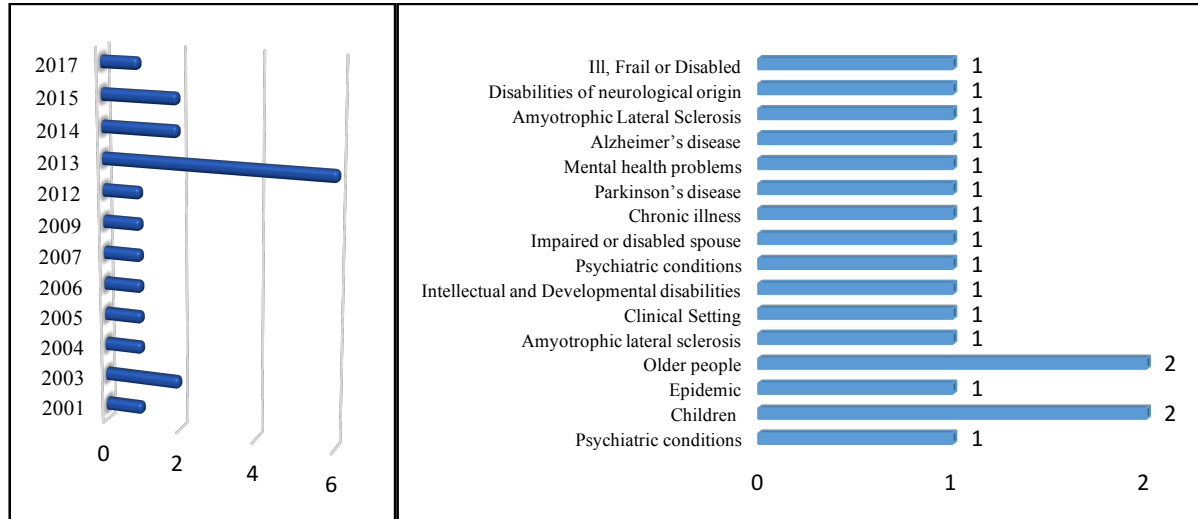


Figure 2: Articles By Year

Figure 3 : Articles By User Type

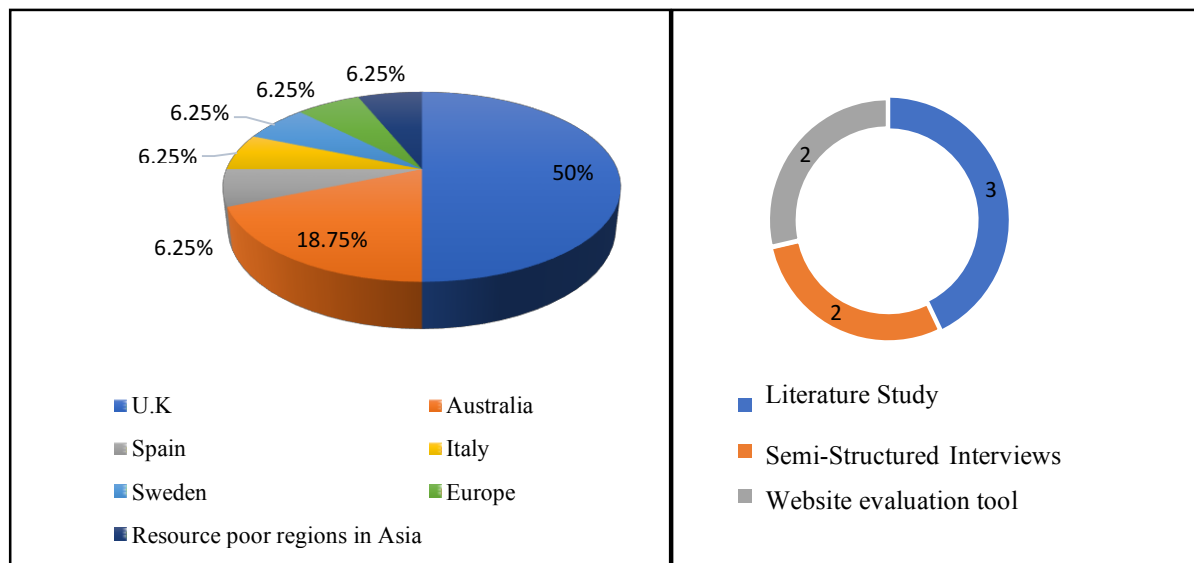


Figure 4: Studies By Country

Figure 5 : Articles By Research Methods

We categorized opportunities and challenges in three primary subcategories namely: (i) Carer Well-being (ii) Care Service, and (iii) Common Opportunities /Challenges. This categorization helps in focusing on critical areas that are concerned with the betterment of carers. Table 2 shows a detailed understanding of the opportunities of supporting carers using online platforms. The first segment is on the Carer Well-being where pieces of evidence have been tabulated supporting claims on how online services in enhancing the state of being healthy and prosperous. The second segment is on Care Service where data are suggesting how various online social platforms have chances to improve the quality of care service provided to patients by the carers. Finally, the third segment articulates the shared opportunities that enhance both carers' health and assistance provided to patients. Similarly, Table 3

has tabulated the three sections concerning challenges of supporting carers using online platforms. In addition, the two tables state in the basis of the caption, description, and study. During the rigorous full-text study of the 20 articles, relevant information concerned with the three categories (Carer Wellbeing, Care Services, and Common Opportunities/Challenges) were coded in NVivo 11 software. That categorization not only helped in obtaining data for demographic results as illustrated above but also contributed to the results in table 2 and 3 as well. The captions that implied goals similar as another one were grouped into a separate joint group.

Table 2 : Opportunities of Carers’ Support Using Online Platforms

| CAPTION | | DESCRIPTION | STUDY |
|-------------------|----------------------------|------------------------------|---|
| CAREER WELL-BEING | Social & Emotional Support | Improve Quality of Life | Individuals who participate in online social groups experience an enhanced quality of life and wellbeing. (Sernani, Claudi & Dragoni 2015) (Loane & D'Alessandro 2013) (Blusi, Asplund & Jong 2013) |
| | | Social Inclusion | Access to online services and online networking enable social inclusion for the carers. (Boulos et al. 2015) (Blusi, Asplund & Jong 2013) |
| | | Reduce Stress | Social support provided by technology helps carers to ease stress. (Surman & Bath 2013) (Perkins & LaMartin 2012) |
| | | Combat Depression/Loneliness | Utilization of online services mitigates social isolation and depression. (Boulos et al. 2015) (Blusi, Asplund & Jong 2013) |
| | | Emotional Support | Carers receive necessary emotional support by the use of emails. (Loane & D'Alessandro 2013) (Perkins & LaMartin 2012) (Mills 2006) |
| | | Reduced Burden | Technology has the potential to ease the sense of burden endured by Carers. (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) |
| | | Feel Secured | Easy access to contact loved ones through Online platforms make Carers feel secure. (Blusi, Asplund & Jong 2013) |
| | | Improved Health | Social supports help in enhancing the Carer's health outcomes. (Loane & D'Alessandro 2013) (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) (Scott et al. 2017) |
| | | Social Support | Social support provided on the Internet lead to improved carer wellbeing (Subirats et al. 2013) (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) |
| Confidence | | Enhanced Self-esteem | Online community services help in bolstering Carer’s esteem levels by providing confidence and well-being. (Loane & D'Alessandro 2013) (Blusi, Asplund & Jong 2013) (Tann, Platts, Welch & Allen 2003) |
| | | Independence | Carers experience greater control of their life while they used the internet. (Blusi, Asplund & Jong 2013) (Tann, Platts, Welch & Allen 2003) |
| | | Empowerment | The Internet has the power to bring social/political change by deploying and empowering disconnected societies such as the Carers. (Perkins & LaMartin 2012) (Tann, Platts, Welch & Allen 2003) |
| | | Personal Development | Older carers can learn various methods to use the internet and ultimately attain new skills and cognitive benefits. (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) |

| | | | | | |
|---------------------|-----------------------------|--|--|--|---|
| | Entertainment | Entertainment | Carers can use internet for hobbies, shopping, leisure and entertainment purposes such as games and music. | (Read & Blackburn 2005) (Blusi, Asplund & Jong 2013) | |
| | Purchasing | Online Care-Related Purchase | Carers can utilise the internet to make purchases for their patients. | (Read & Blackburn 2005) | |
| CARE SERVICE | Enlightenment | Information Dissemination | Internet helps in attaining information on topics such as diseases. | (Perkins & LaMartin 2012) (Tann, Platts, Welch & Allen 2003) | |
| | | Enhance Knowledge | Online Healthcare Information helps to enhance knowledge regarding the patient's condition. | (Surman & Bath 2013) (Read & Blackburn 2005) | |
| | | Promote Patient Health Literacy | The Internet provides a vast range of information and eventually help in enhancing one's knowledge. | (Hogden, Greenfield, Nugus & Kiernan 2013) | |
| | Treatment Awareness | Evaluate Availability & Effectiveness of Treatment | The Internet can be used to critically examine the accessibility and productiveness of the treatments suggested by doctors. | (Tann, Platts, Welch & Allen 2003) | |
| | Advanced Care | Monitor patient's evolution | Carers can examine patient's health status by using the new social platform and also compare the results with other patient's status. | (Subirats et al. 2013) (Sernani, Claudi & Dragoni 2015) | |
| | | Improved Care Practice | By attaining knowledge from online, Carers can enhance the patient's recovery procedure and result. | (Surman & Bath 2013) (Sernani, Claudi & Dragoni 2015) (Blusi, Asplund & Jong 2013) | |
| | | Test Aspects of Care | Online information enables individuals to critically examine the care service deployed and be aware of plus and minus of the suggested treatment method. | (Tann, Platts, Welch & Allen 2003) | |
| | COMMON OPPORTUNITIES | User-Friendly | Convenience | The online support network is convenient as it is available round the clock and also avoids the need to travel.. | (Read & Blackburn 2005); (Subirats et al. 2013); (Loane & D'Alessandro 2013); (Bath & Bouchier 2003); (Dodsworth et al. 2013); (Boulos et al. 2015); (Blusi, Asplund & Jong 2013) (Tann, Platts, Welch & Allen 2003) (Perkins & LaMartin 2012) (Mills 2006) |
| | | | Speed | The Internet provides faster information as compared to other conventional methods. | (Read & Blackburn 2005) (Perkins & LaMartin 2012) (Mills 2006) |
| | | Flexibility | The online systems are flexible to updates and can install latest technologies with ease. | (Read & Blackburn 2005) (Sernani, Claudi & Dragoni 2015) | |

| | | | |
|--------------------------|--|--|--|
| Information Articulation | Information Delivery | The internet can disseminate a mix of public/private information and services for Carers. | (Surman & Bath 2013) (Blackburn, Read & Hughes 2005) ; (Read & Blackburn 2005) (Subirats et al. 2013); (Loane & D'Alessandro 2013); (Gray & Robinson 2009); (Dodsworth et al. 2013); (Boulos et al. 2015) (Lucas 2014); (Perkins & LaMartin 2012) (Timmons 2001); (Scott et al. 2017); (Mills 2006) |
| | Cost-Effective Information Dissemination | The Internet can provide crucial inexpensive information for both older people and their Carers. | (Yardley & Nyman 2007) |
| Well-founded Information | Tailored advice | Carers can tailor their online advice package depending on their requirements, capabilities, and choice. | (Subirats et al. 2013) (Yardley & Nyman 2007) (Blusi, Asplund & Jong 2013) |
| | More Informed Opinion | Advanced social networking has the potential to support information democratisation, Carer authorisation and informed judgments. | (Subirats et al. 2013) (Loane & D'Alessandro 2013) |

Table 3 : Challenges of carers using online platforms

| | CAPTION | DESCRIPTION | STUDY |
|------------------------|------------------------------|--|---|
| CARER WELLBEING | Lack of Specific Information | Little Information for Young Carers | Lack of information available regarding the relevance of technology in the lives of young Carers. (Gray & Robinson 2009) |
| | | Little Information for Aging Carers | Lack of information available regarding the relevance of technology in the lives of aging Carers. (Perkins & LaMartin 2012) |
| | False Intimacy | The Internet can create a sense of fake friendship. | (Perkins & LaMartin 2012) |
| | Require Expert Advice | Carers might need expert advice on a matter such as finance depending on their state and location. | (Bath & Bouchier 2003) |
| CARE SERVICE | Reliability | The internet is home to a broad variety of unchecked information. | (Surman & Bath 2013) (Blackburn, Read & Hughes 2005); (Lucas 2014); (Timmons 2001); (Hogden, Greenfield, Nugus & Kiernan 2013) |
| | Lack of Transparency | The lack of transparency leads to its limited use. | (Scott et al. 2017) |
| | Confidentiality | Users limited the use of emails while they had to carry out confidential tasks. | (Mills 2006) |

| | | | | |
|--------------------------|------------------------------|-----------------------------------|---|---|
| COMMON CHALLENGES | Technical Lag | Technical Lag during Emergency | Upgrades to online platforms could cause technical lag, and cause stressful situations during a crisis. | (Blackburn, Read & Hughes 2005) (Mills 2006) |
| | Usability Issue | Difficult to Understand | Professionally styled graphics and unlimited information online make it difficult for the Carers to comprehend. | (Subirats et al. 2013) (Bath & Bouchier 2003) (Yardley & Nyman 2007) |
| | | Suitability | Interactive websites have been observed not to be suitable for the aged individuals. | (Yardley & Nyman 2007) |
| | | Accessibility | A significant portion of users faces internet access issues while using mobile devices. | (Timmons 2001) (Scott et al. 2017) |
| | Misinterpretation | Misinterpretation | Misconceptions are restricting carers from utilising the internet in mobile devices. | (Timmons 2001) (Scott et al. 2017) (Mills 2006) |
| | Irrelevant | Irrelevant | Many Carers tend to find irrelevant information on the internet. | (Subirats et al. 2013) (Yardley & Nyman 2007) (Perkins & LaMartin 2012) |
| | Lack of Time | Lack of Time | Due to high work demand, the Carers find it hard to get time to use the internet. | (Read & Blackburn 2005) |
| | | Digital Gap | Readability | Majority of the existing social network focus on only Carers with high readability levels whereas the others are ignored. |
| | Socio-Demographic Factors | | Factors such as shortfall of money, age and low literacy level and much more make accessibility a challenge for the Carers. | (Blackburn, Read & Hughes 2005); (Read & Blackburn 2005) (Dodsworth et al. 2013) (Blusi, Asplund & Jong 2013) (Tann, Platts, Welch & Allen 2003); (Perkins & LaMartin 2012) |
| | Information- Related Hurdles | Insufficient Information | Carers find difficulty in finding the necessary information or websites when required. | (Surman & Bath 2013) (Read & Blackburn 2005) |
| | | Quality & Accuracy of Information | The lack of restriction on the content published online requires Carers to be extra cautious regarding the quality of health-related information available. | (Surman & Bath 2013) (Bath & Bouchier 2003) (Boulos et al. 2015) (Tann, Platts, Welch & Allen 2003) (Perkins & LaMartin 2012) |
| | | Complexity | There is a need to simplify and enhance websites for better use by Carers. | (Read & Blackburn 2005) (Dodsworth et al. 2013) (Boulos et al. 2015) |
| | Anxiety | Anxiety | Many family Carers are scared and reluctant to use the technology. | (Read & Blackburn 2005) (Dodsworth et al. 2013) (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) |

| | | | |
|-----------------------------|-----------------------------|---|---|
| Lack of Support | Lack of Support | The insufficient assistance and inspiration to use technology play as a hurdle for Carers. | (Blusi, Asplund & Jong 2013) (Perkins & LaMartin 2012) |
| Communication Breakdown | Communication Breakdown | Due to the absence of human contact, there is a high chance for misunderstandings to rise online. | (Hogden, Greenfield, Nugus & Kiernan 2013) (Perkins & LaMartin 2012) |
| Preference to Other Methods | Preference to Other Methods | Some users prefer in-person meetings over online communications due to its higher personal touch. | (Octoman & McLean 2014) (Dodsworth et al. 2013) |

Discussion and Future Research

This study conducted a systematic literature review to analyse the opportunities and challenges of supporting carers using online platforms. From the 20 selected articles, we extracted a set of opportunities and challenges and categorized them in three groups as illustrated in table 2 and 3, and their implications have been discussed below:

Carer Wellbeing

Broadly, we extracted a total of three high-level opportunities and three challenges for carer's wellbeing. Many carers felt they could attain confidence, entertainment and social and emotional support from online services. On the other side, a section of people felt they did not obtain the information they were looking for, experienced fake connections, or had to obtain a second opinion through traditional methods. However, the challenges seem to be solvable. Carers can be educated to search specific topics online. Through online community groups, they can raise issues and try to capture the attention of subject experts. To eradicate the concerns on malicious intimacy, users can interact online through video chat facilities to feel more connected instead of just texts. Furthermore, people can directly contact specialists in case of doubts through various online medical platforms available. On the bright side, carers feel more mentally healthy and supported by social groups online. Hence, by deploying solutions for the downsides, carers have significant opportunities to improve their wellbeing from the online service.

Care Service

The crucial positives of Care Service by using online social platforms include knowledge enhancement, ability to shop medical items, ability to check the availability of suggested treatments, critically analyse advised treatment and improve care practices. Alternatively, the challenges such as trust issues, a chance of delusion, and difficulty in usage, slow online speed and discursion are alarming. It is imperative to address such issues since it can otherwise lead to adverse situations for both carers and patients. Although carers have an incredible opportunity to attain valuable information online, many pieces of information are unregulated and posted by inexperienced personnel. One of the ways to address the issue is by holding awareness programs for carers before using the internet for caregiving duties. As suggested by Timmons (2001), the nurses in hospitals can take up the role as educators to not only teach the use of internet but also attain skills to evaluate online information. This way we can avoid the chance of mishaps due to usability issues and misunderstanding of

information. While experts such as nurses can educate carers, they feel more confident in assessing and examining the information they obtain online. Blackburn, Read & Hughes (2005) observed technical lags during online updates. Such lags do not occur in all scenarios, and the web developers need to be informed of the possible discomforts caused by them. Opportunities to purchase medical items would be highly convenient for carers when they are unable to obtain such items in nearby stores or when they are in a situation that they cannot leave the patient alone and go shopping. Moreover, it is beneficial for carers to be well informed of the treatments advised by doctors to make wise decisions.

Common Opportunities/Challenges

On the bright side, a group of carers found the Internet user-friendly and an excellent source of information amongst which some were tailored according to the user types. The government officials can play a vital role in mitigating issues such as the digital gap. The carers in need could be funded and be educated at any non-profit service centers. The training facilities can also ease the problem of lack of support and anxiety. As users come across other carers with similar challenges, they could feel comforted and encouraged. As noted by Dodsworth et al. (2013) there is a need for developers to simplify content online for the better use by carers. Awareness/Training centers can educate users on which websites are reliable and which are not. Online conflicts occur in other platforms as well. Hence, it seems to be an issue, which can be minimized by instructing users on how to control rage in unfavourable situations. The preference of users on other methodologies other than online platforms could be due to lack of familiarity or insufficient knowledge on using the internet. The reasons can be varied. Hence, it will not be possible to propose a single resolution. One of the solutions could be to help carers get exposure to online services so that they can be motivated to try the facility.

Recommendations for the future research

Given that only 20 articles were selected for the final review, future studies are encouraged to widen the search and include more past studies for analysis. Furthermore, empirical research is recommended in the future to collect evidence from carers, as the users of particular online social platforms, in regards to how and why engagement with others may impact their wellbeing and decision making choices impact. Future studies are also encouraged to use novel theoretical perspectives for explaining potentials of online social networks for carers. For example, Abedin and Qahri-Saremi (2018) encourage adoption of service innovation framework and models, such as service-dominant logic, for theorising why users are increasingly interacting, innovating, and learning via social computing technologies. According to these scholars, the traditional notion of service environment for organisations is being redefined in form of a digital space that is more socially embedded and necessarily more fluid in its time-space design. Therefore, organizations that provide support services to carers need to review their online social presence to facilitate and encourage engagement with carers, spend more time with them online, and extract useful insights from online discourse for better decision makings.

References

- Abedin, B. 2016. "Diffusion of adoption of Facebook for customer relationship management in Australia: An exploratory study". *Journal of Organizational and End User Computing*, (28:1), pp. 56-72.
- Abedin, B., Talaei-Khoei, T. and Ghapanchi, A. 2013. "A review of critical factors for communicating

- with customers on social networking sites”, *International Technology Management Review* (3:4), pp.208-218.
- Abedini, A., Abedin, B., Miliszewska, I. 2017. “Peer to Peer Adult Learning Engagement in Online Collaborative Learning: Characteristics and Learning Outcomes”, *Twenty First Pacific Asia Conference on Information Systems 2017, PACIS*, Langkawi, pp.1-12.
- Abedin, B., and Qahri-Saremi, H. 2018. “Introduction to the Special Issue—Social Computing and Service Innovation: A Framework for Research”. *Journal of Organizational Computing and Electronic Commerce*, (28: 1), pp. 1-8.
- Bath, P.A. & Bouchier, H. 2003. “Development and application of a tool designed to evaluate web sites providing information on alzheimer's disease”, *Journal of Information Science* (29: 4), pp. 279-297.
- Bee, P.E., Barnes, P. and Luker, K.A. 2009. “A systematic review of informal caregivers’ needs in providing home-based end-of-life care to people with cancer”, *Journal of clinical nursing* (18:10), pp.1379- 1393.
- Blackburn, C., Read, J. & Hughes, N. 2005. “Carers and the digital divide: factors affecting Internet use among carers in the UK”, *Health & Social Care in the Community* (13:3), pp.201-210.
- Blusi, M., Asplund, K. & Jong, M. 2013. “Older family carers in rural areas: experiences from using caregiver support services based on Information and Communication Technology (ICT)”, *European Journal of Ageing* (10:3), pp.191-199.
- Boulos, M.N.K., Ifeachor, E., Escudero, J., Zhao, P., Carroll, C., Costa, P., Doppler, G., Marín, L.C., Spuru, L., Guðmundsdóttir, K.H. & Kosem, M. 2015. “LiveWell—Promoting Healthy Living and Wellbeing for Parkinson Patients through Social Network and ICT Training: Lessons Learnt and Best Practices”, *International Journal of Healthcare Information Systems and Informatics (IJHISI)* (10:3), pp.24-41.
- Breskovic, I., De Carvalho, A.F.P., Schinkinger, S. and Tellioglu, H. 2013. “Social awareness support for meeting informal carers needs: early development in TOPIC”, *ECSCW 2013*, ECSCW, Paphos, Cyprus, pp.3-8.
- Dodsworth, J., Bailey, S., Schofield, G., Cooper, N., Fleming, P. and Young, J. 2012. “Internet technology: An empowering or alienating tool for communication between foster-carers and social workers?”, *British Journal of Social Work* (43:4), pp.775-795.
- Erfani, S. S., Blount, Y., & Abedin, B. 2016. “The influence of health-specific social network site use on the psychological well-being of cancer-affected people”. *Journal of the American Medical Informatics Association*, (23:3), pp. 467-476.
- Erfani, S. S., Abedin, B., & Blount, Y. 2017. “The effect of social network site use on the psychological well-being of cancer patients”. *Journal of the Association for Information Science and Technology*, (68:5), pp. 1308-1322.
- Foster, M. and Chaboyer, W. 2003. “Family carers of ICU survivors: a survey of the burden they experience”, *Scandinavian Journal of Caring Sciences* (17:3), pp.205-214.
- Gray, B. & Robinson, C. 2009. “Hidden children: Perspectives of professionals on young carers of people with mental health problems”, *Child Care in Practice* (15:2), pp.95-108.
- Greenwood, N., Mackenzie, A., Cloud, G.C. and Wilson, N. 2009. “Informal primary carers of stroke survivors living at home—challenges, satisfactions and coping: a systematic review of qualitative studies”, *Disability and rehabilitation* (31:5), pp.337-351.
- Hogden, A., Greenfield, D., Nugus, P. & Kiernan, M.C. 2013. “What are the roles of carers in decision-making for amyotrophic lateral sclerosis multidisciplinary care?”, *Patient preference and adherence* (7), p.171.
- Hu, C., Kung, S., Rummans, T.A., Clark, M.M. and Lapid, M.I. 2014. “Reducing caregiver stress with internet- based interventions: a systematic review of open-label and randomized controlled trials”, *Journal of the American Medical Informatics Association* (22:e1), pp.e194-e209.
- Janda, M., Neale, R.E., Klein, K., O'Connell, D.L., Gooden, H., Goldstein, D., Merrett, N.D., Wyld, D.K., Rowlands, I.J. and Beesley, V.L. 2017. “Anxiety, depression and quality of life in people with pancreatic cancer and their carers”, *Pancreatology* (17: 2), pp.321-327.

- King, R., Bickman, L., Shochet, I., McDermott, B. and Bor, B. 2010. "Use of the internet for provision of better counselling and psychotherapy services to young people, their families and carers", *Psychotherapy in Australia* (17:1), p.66.
- Lucas, H. 2015. "New technology and illness self-management: Potential relevance for resource-poor populations in Asia", *Social Science & Medicine* (145), pp.145-153.
- Loane, S.S. & D'Alessandro, S. 2013. "Communication that changes lives: Social support within an online health community for ALS", *Communication Quarterly* (61:2), pp.236-251.
- Maiden, N., D'Souza, S., Jones, S., Müller, L., Pannese, L., Pitts, K., Prilla, M., Pudney, K., Rose, M., Turner, I. and Zachos, K. 2013. "Computing technologies for reflective, creative care of people with dementia", *Communications of the ACM* (56: 11), pp.60-67.
- Mills, S. 2006. "When humans need humans: The lack of use of computer-based ICT in distance pastoral care", *Interacting with Computers* (18:4), pp.556-567.
- Namkoong, K., DuBenske, L.L., Shaw, B.R., Gustafson, D.H., Hawkins, R.P., Shah, D.V., McTavish, F.M. and Cleary, J.F. 2012. "Creating a bond between caregivers online:effect on caregiver's coping strategies", *Journal of health communication* (17: 2), pp.125-140.
- Nolan, M. and Dellasega, C. 2000. "I really feel I've let him down": supporting family carers during long-term care placement for elders', *Journal of Advanced Nursing* (31:4), pp.759-767.
- Octoman, O. & McLean, S. 2014. "Challenging behaviour in foster care: what supports do foster carers want?", *Adoption & Fostering* (38:2), pp.149-158.
- Perkins, E.A. & LaMartin, K.M. 2012. "The Internet as social support for older carers of adults with intellectual disabilities", *Journal of Policy and Practice in Intellectual Disabilities* (9:1), pp.53-62.
- Read, J. & Blackburn, C. 2005. "Carers' perspectives on the internet: implications for social and health care service provision", *British Journal of Social Work* (35:7), pp.1175-1192.
- Scott, K.M., Nerminathan, A., Alexander, S., Phelps, M. & Harrison, A. 2017. "Using mobile devices for learning in clinical settings: A mixed-methods study of medical student, physician and patient perspectives", *British Journal of Educational Technology* (48:1), pp.176-190.
- Sernani, P., Claudi, A. & Dragoni, A.F. 2015. "Combining artificial intelligence and netmedicine for ambient assisted living: A distributed BDI-based expert system", *International Journal of E-Health and Medical Communications (IJEHMC)* (6:4), pp.62-76.
- Subirats, L., Ceccaroni, L., Lopez-Blazquez, R., Miralles, F., García-Rudolph, A. & Tormos, J.M. 2013. "Circles of Health: Towards an advanced social network about disabilities of neurological origin", *Journal of biomedical informatics* (46:6), pp.1006-1029.
- Surman, R. & Bath, P.A. 2013. "An assessment of the quality of information on stroke and speech and language difficulty web sites", *Journal of Information Science* (39:1), pp.113-125.
- Tann, J., Platts, A., Welch, S. & Allen, J. 2003. "Patient power? Medical perspectives on patient use of the Internet", *Prometheus* (21:2), pp.145-160.
- Timmons, S. 2001. "Use of the Internet by patients: not a threat to nursing, but an opportunity?", *Nurse Education Today* (21:2), pp.104-109.
- Torp, S., Bing-Jonsson, P.C. and Hanson, E. 2013. "Experiences with using information and communication technology to build a multi-municipal support network for informal carers", *Informatics for Health and Social Care* (38:3), pp.265-279.
- Tsigaropoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I. and Deliveliotis, C. 2009. "Problems faced by relatives caring for cancer patients at home", *International Journal of Nursing Practice* (15:1), pp.1-6.
- Yardley, L. & Nyman, S.R. 2007. "Internet provision of tailored advice on falls prevention activities for older people: a randomized controlled evaluation", *Health promotion international* (22:2), pp.122-128.