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## **”The web is not enough, it's a base” - an explorative study of what needs a web-based support system for young carers must meet.**

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### **Abstract**

**Aim:** The aim of this study was to gain knowledge about the specific needs that a web-based support system for young carers must meet. **Methods:** Twelve young people with experience of caring for and supporting a close friend, partner or relative with mental illness were interviewed about their life situation, support needs and opinions about a hypothetical web-based support system. The transcribed interviews were analysed using content analysis. **Results:** The analysed data were organised into three themes relating to support needs, each including a number of sub-themes: *knowledge* – understanding mental illness, managing the mentally ill person, and self-care; *communication* – shared experiences, advice and feedback, and befriending; and *outside involvement* – acute relief, structured help and health care commitments. **Conclusion:** Web-based support for young carers may be a suitable way to meet the need for knowledge and to meet some of the needs for communication. We have outlined a concept of a geographically anchored web support to meet the need for befriending, facilitate connections to health and social care, and increase understanding and interaction between the parties involved. Further research is needed to corroborate the results.

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**Key words:** *Internet, Needs, Support, Young carers, Web*

## 1. Introduction

During the last 15–20 years [1] there has been growing evidence that some children and young people carry an extensive care burden in relation to physical and/or mental illness (MI) in their families. The concept of *young carer* (YC) which was coined in a British research context is now a widely accepted term for carers up to 18 years of age [2]. It is hard to estimate how many children are affected and to what degree. A rough (minimal) value with cross-national validity for the percentage of children with some kind of care burden is around 2–4% of the population [2], according to the YC definition [2]. However, disregarding this definition and talking in general terms of children who are close to a parent with some kind of addiction or physical or MI, this proportion will multiply several times [2]. The impact that a parent's or sibling's illness has on a child's life situation may include changes of role, switching of roles between child and parent, and increasing responsibilities [3]. The general view is that YCs are negatively affected by the care situation, particularly in cases where the situation is long-term [4] and the child or young person has no healthy adults to turn to and rely on [5]. Young carers are at risk of becoming isolated and socially excluded and experiencing problems with school [6]. They may have to restrict their leisure time, leading to difficulty in maintaining friendships [6].

One way to manage the caring situation is to integrate it into one's life [3,7], which could result in building one's identity around being a carer. This has been reported to be connected to feelings of competence and positive self-esteem and at the same time to be a way to “combat feelings of uncertainty and isolation” [7]. It has also been reported that YCs' sense of

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being mature and the practical skills they acquire through the caring experience seem to be outweighed by “restricted educational, social and career opportunities” [8]. However, the impact on a child of being a carer may not be altogether negative; rather, the impact is dependent on the length of the burden and the degree to which the care situation corresponds to the child’s age, maturity, and ability to understand [4]. Several authors stress that there is a lack of knowledge about YCs’ own opinions, experiences and thoughts about themselves and their situation [3,4,7]. It has furthermore been stated that YCs in all countries still are a vulnerable group in need of support and recognition [2].

The concept of YC covers caring for physically as well as mentally ill family members. In Sweden, the focus since the mid-1990s has been on children’s exposure in families with MI or addiction [9,10]. Awareness has been growing, and further studies have been published that allow the voices of the children to be heard [11,12].

There are support groups for YCs in many municipalities in Sweden [13], often offered by the social care system and sometimes by the health care system. In 2010 the Swedish Health and Medical Services Act was amended [14]. It now states that health care personnel are obliged to find out whether an ill person has any children and to ensure that these children's needs for support, information and guidance are met. Still, it is unlikely that all children will be reached.

In the early 1990s, web-based social support networks began to emerge [15], and the increased availability of computers and Internet connectivity has accelerated their presence. Although there are a number of websites intended to support YCs, very little research has been carried out in the field. The web has been touted as a way to overcome isolation [6], and to connect with others in a context where there is less pressure to identify oneself [16]. Professionals meeting YCs have proposed the use of the Internet to raise awareness of the

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existence of YCs [17]. The lack of research into the use of technology to support this group has also been pointed out [17]. There are some, albeit few, studies of web technology use to support young people in other health-related contexts [18-21].

In the present study we extend the definition of YC [2] to include young people aged between 16 and 25 who are close to and supporting a parent, sibling, other relative, friend, or girlfriend/boyfriend with MI. The literature reveals at least four reasons why a web-based support system would be suitable for this group of young carers:

- Young carers may have specific problems in transition to adulthood, and are at risk of being isolated with their burden [1,8].
- Young people's mental health has worsened in Sweden to a higher degree than in many other countries and the decline is continuing [22,23]. Living close to someone with MI may increase vulnerability.
- Web-based media play a central role in the lives of young people. In Sweden, 90–95% of 16–25-year-olds use the Internet on a regular basis at home, and 50% of 5-year-olds have already used the Internet [24].
- A web-based support system would have the potential to reach a great number of young people and help them connect with each other. It would provide them with opportunities to share their experiences and allow them to announce their presence at their own pace. It would also be able to provide information and offer links to other sources [24,25].

A website may be a highly suitable support area where YCs can connect with others, break their isolation, obtain relevant facts and psychologically normalise their situation. However, to our knowledge, there has been no previous study which systematically collects and

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structures the user data which would be relevant for building such a web-based support system. The aim of the present study was to explore and describe the support needs of YCs, aged 16–25, in relation to their life situation and in the context of a hypothetical web-based support system.

## **2. Methods**

### *2.1. Design*

We chose a qualitative, descriptive design to explore the YCs' needs. As we wanted our results to be easy to relate and apply to a web-based support system, it was important to choose an analytical method that could categorise the data in a relevant way. Content analysis was selected as a suitable method meeting these criteria.

Ethical approval for the study was granted by the regional ethical review board of Gothenburg, Sweden (Dnr 762-08).

### *2.2. Participants and setting*

Participants were recruited from a region in southwest Sweden via leaflets, newspaper advertisements, and websites. The main message in the recruitment information corresponded to the inclusion criteria and information on the aim of the project, namely to build and evaluate a website intended to support young people close to and supporting someone with MI. The information also included a phone number and a website address for those who wished to express their interest in participating. The inclusion criteria were: (1) being aged between 16 and 25; (2) being close to and supporting someone with a MI, specifically a parent, sibling, other relative, friend, or girlfriend/boyfriend. The exclusion criterion was

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being unable to understand, read or speak Swedish. Twelve young people (nine women and three men) were included and interviewed (Table I).

INSERT TABLE I ABOUT HERE, PLEASE

### *2.3. Data collection*

All participants were informed about the study and its aim, and signed a document of informed consent. This document clearly stated that the confidentiality of the participants and the interview data would be protected. It also stated that studies utilising the data would be presented in a way that would not compromise participants' confidentiality. The participants were given the opportunity to ask questions about the study by email or by phone. In connection with the interview, questions could be asked in person. Participants could choose how they wished to participate – in a focus group or in individual interviews.

The data collection included both focus group (n=4) and individual interviews (n=8). The individual interviews consisted of four telephone interviews and four face-to-face interviews (Table I). The different interview types all followed the same interview guide in a semi-structured manner. The interviews started with a section where participants were asked about themselves and the person(s) they supported. There followed three blocks of questions with a time perspective: (1) questions about when the supported person became ill; (2) questions about the present situation; (3) questions about the imagined future. The interviews concluded with questions about the participants' use and experiences of the Internet and their opinions about a hypothetical web-based support system. Besides the supported person(s), there were other persons mentioned by the participants, who added to their care load. Five participants



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described problems with a “healthy” parent, including emotional detachment, alcoholism and conflict making. One participant received frequent calls from a supported friend’s relatives. One participant was worried about her brothers who still lived with the person with MI (PM) and one participant had a friend whose parent committed suicide.

The interviews were conducted by the authors: two senior researchers (I.S. and B.K.) and one PhD student (M.E.), all with previous experience of performing semi-structured interviews. The individual interviews lasted approximately 1 hour each. The focus group interview lasted approximately 1½ hours and was performed by the two senior researchers, with the PhD student acting as observer. All interviews were tape-recorded and transcribed verbatim. The focus group and face-to-face interviews took place on the university campus near the participants’ homes.

### *2.4. Data analysis*

The transcripts were read through several times to achieve familiarity with the content. A problem-driven content analysis inspired by Krippendorff [26] was performed with the aim of uncovering support needs. One interview or focus group session was regarded as a unit of analysis and Atlas.ti [27] was used for coding.

Codes were kept as close to the text as possible and the coding process was performed in three domains: (1) expressed support needs related to the care situation; (2) expressed support needs related to a hypothetical web-based support system; and (3) inferred support needs related to the care situation. An expressed support need was defined as a clearly stated need or wish, such as “I would have needed advice from ...”, “I need someone to talk to ...”, “It should be possible to talk to others ...”. In these examples the need for support was clearly and

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explicitly stated. However, some support needs were inferred from clinical judgements based on the interview data. For instance, there were several quotations about the participants being in an exposed position where they were accused, felt helpless, or found themselves cornered or in a position where they just felt bad.

Well, you apologise 'cause you were there, just because you actually were there, 'cause you were available for attack or so. You apologise, but it was the other one who ought to have done it [i.e. apologised].

Sometimes it becomes almost like ... when you're trying to help he gets irritated and then ... – Why do you care, you don't understand anyway!

I think we both understood that the [relationship was going to end] ... 'cause those times when we met at the end, he was just crying ... it was that bad.

From quotations like these we inferred the need to know about how to protect one's self-integrity, to psychologically separate oneself from the PM, and to care for oneself. This judgement process regarding inferred needs was made by the authors and based on their professional backgrounds in psychology, psychiatry and rehabilitation, and as researchers on the carers' perspective.

The analysis included a circular process of revisiting codes and rereading the texts as a whole. The codes were organised into three themes, which were further processed into sub-themes. We primarily organised codes from domains one and two, adding codes from domain three only if they represented a need not already present in the other two domains.

### 3. Results

The results were organised into three themes, covering different support needs: *knowledge, communication, and outside involvement*. The sub-themes are presented with the themes, and each theme is described in the three domains: (1) expressed support needs related to the care situation; (2) expressed support needs related to a hypothetical web-based support system; and (3) inferred support needs related to the care situation.

#### *3.1. Knowledge: understanding mental illness, managing the person with mental illness, and self-care*

... to learn about other people's situations ... a movie or information about how to talk to someone who is manic, and how to support that person ... [ ] information of where to turn to get help.

The participants expressed a need to know more about different types of MI, about the course of the illness and about the consequences both for the PM and for the people close to the PM. The need for concrete information and advice was also expressed, and participants suggested that both information and advice could be supplied by the health care system, once contact had been established, for example through leaflets about what could be expected regarding PMs. Early information about MI in school was seen as a way to be better prepared: "We have sex education, so why not education about MI?"

In relation to the hypothetical website, the participants wanted rich descriptions, divided into the different types of MIs, as opposed to "the super short [descriptions] you can find

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everywhere”. These descriptions should cover all forms of decreased mental health, not just the severe forms. The participants called for a way to identify the PM’s disease or state and suggested the use of broad descriptions corresponding to a particular group of MIs, which then could be followed by more details – in other words, a funnel model. Another suggestion was the use of some kind of guide, including Yes/No questions in which Yes (and No) answers lead to follow-up questions, narrowing the user down to an answer and some advice. Once advice has been acted on, it should be possible to get feedback in a similar way, for example: “Did this advice work? Yes/No”, again with follow-up questions for either answer.

In relation to knowledge about the disease itself, the participants mentioned that it is important to add information about causes of the illness. In this way the illness could be understood, and this would also reassure the YCs that they were not the cause of the MI. It was pointed out that facts about other behaviours not primarily related to MI should also be provided, for example assault, sexual assault, and bullying. Another type of desired knowledge concerned legal and financial advice, a need that could arise from situations of addiction and mania, for example. Statistics about young people in a care situation and about the prevalence of MI were seen as a way to psychologically normalise the YC’s situation. Also, several participants suggested featuring others’ life stories on video or in text form, and also expressed the importance of presenting everyday life and common experiences, not just severe or extreme cases. Finally, participants felt that as much knowledge as possible should be available on this one website.

Within this theme we inferred needs related to self-care. It seemed important for the participants to know how to protect their integrity, preserve self-confidence, manage guilt and reduce self-blame, and to know when it was necessary to call for help. We also inferred the importance of building the own life space, for example by engaging in a hobby or a special

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interest, meeting with friends, having fun, and keeping up with school work.

### *3.2. Communication – shared experiences, advice and feedback, befriending*

... it [the hypothetical website] shouldn't just be a bunch of text. In that case you could just as well search on Google, but I think it should be somewhere that you feel you can make contact.

Communicating about their situation and sharing experiences with others in the same situation was a frequently expressed need among the participants, as was getting in touch with professionals, support groups, and other adults. The participants explained that in taking up contact with adults, they would want to talk, explore their thoughts and obtain advice. It was considered important that the adult contact person would really understand what the caring situation was like and what it meant to the YC. As one female participant expressed it, “Someone who understands the severity ... it wouldn't be enough for me if somebody just told me to leave [the situation].”

In relation to the hypothetical website, the participants expressed the need to exchange, discuss and share their experiences in a peer support group. They also mentioned the possibility of doing this anonymously and without shame. Technically this could be achieved through a forum board or chat room, but a forum board would be “better suited, 'cause the information is always left there”. The possibility to have a more personal contact was also mentioned and proposed to be achieved via e-mail. The web-based support system was talked about as a “beginning” or a “base”; some participants expressed the wish that it might lead to a real-life contact. The participants expressed the need to ask questions and get answers from

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professionals who recognised their situation – professionals working for the website – whether via phone, e-mail, chat or other, similar functions. Another type of sharing related to communication was the possibility to post their own articles, tips or links to articles and be able to read those posted by others.

Within this theme we inferred a need to facilitate communication about MI and its consequences. The YCs were not fully able to talk openly about these issues, because of the taboos and associated stigma related to them.

### *3.3 Outside involvement – acute relief, structured help, health care commitments*

You need support. You need to know that the patient is in good hands, that there are treatment centres ... a little more individual support [for the PM], so that you don't need to do all the supporting ... somewhere you can call when there's a crisis.

The need for outside involvement was expressed in several ways. It often involved relations with health care and family. There was a wish that the health care personnel who were in contact with the PM could see and support the whole family and, where applicable, also pay attention to close friends. It was important for YCs to know that the PM was in good hands within the health care system and had someone to talk to. They also wanted to be sure that steps were being made to prepare the PM to return to normal life. They suggested that PMs should be provided with leaflets to raise their awareness of their mental health state and thus increase their willingness to engage in treatment. The participants wished for greater involvement in the care process, and to be listened to and taken seriously; they also expressed

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the wish to be relieved from some of the responsibility. One example of greater involvement was put as follows: “just going with [my mother] to the welfare officer could have helped”.

There was also a demand for more thought-out, persistent and caring health care. One example was the need to coordinate discharges with the family, and not automatically taking the patient’s word for it when he or she said that everything was all right. As one participant expressed it, health care should take initiative for providing support in the home: “In such case [when nothing works at home] of course there is a need that someone else comes home and, like, ‘Hey, now we do it like this!’” One of the participants also mentioned that the laws covering PMs were too weak. This participant asked for information on how to influence health care and politicians in that respect and in general how to influence progression in health care. Others expressed a desire for action by people outside the health care system, like parents and other adults. However, adults were perceived to not always understand the impact that for instance, a mentally ill friend could have on the life of a YC.

Regarding the hypothetical website, the importance of outside involvement corresponded to the need for links to support resources that could potentially impact on the situation of the YC. The participants suggested links to different authorities, like the police or the home municipality, as well as links to women’s shelters and health care organisations, with tips on how to “get in” (i.e. how to access the help that is available). Links like that were considered important “... so you don’t need to fight and fight without succeeding in getting help”, or, as expressed by another person, “It might not be that fun to call the municipal switchboard, ‘Hi, I am a relative of a PM, I have never had a problem myself, what do I do?’”

We inferred a number of related support needs within this theme. We identified the need to help the YCs keep up with their school work; and to ask about their situation and, where necessary, act on it. It was not uncommon for the participants to describe difficulties with

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school work due to their caring situation. We also identified a need for many YCs who had passed compulsory school age to get help with further education (and, where applicable, employment).

### **4. Discussion**

#### *4.1. Discussion of results*

It has been proposed that any intervention directed at YCs must be grounded in their own stated needs [1]. However, research among YCs usually deals with life experiences, life context, and evaluation of projects supporting YCs, and rarely focuses on the support needs. This study makes support needs the subject of interest, and also offers information about what YCs consider essential in a web-based intervention aimed at meeting these needs.

Other researchers who have presented support needs in an aggregated form [1,5,28] have offered lists of needs, but have not structured them into themes. The structured form is of particular value if the outcome is to be used in a technology application with a specific need to know what the application is supposed to do.

The results of this study revealed three types of support needs among our participants. These needs could be viewed as having different qualities, but could also be viewed as incorporating different degrees of involvement with other people relevant to this special context.

Knowledge-based needs require only a low degree of involvement with other people. These needs can be subdivided into *understanding MI*, *managing the PM*, and *self-care*. Addressing knowledge needs is a common way of supporting families with MI and addiction; it is used by different support services and is in line with psycho-educational methods. Having



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an understanding of the MI has been emphasised as an especially important way for children to grasp the situation and to survive it [5]. Indeed, the sub-themes described in this theme corresponded very much to the everyday lives of the YCs: how to understand, how to manage, and how to take care of oneself.

Thinking about the hypothetical website generated a number of ideas. Web technology opens up many possibilities to structure and present knowledge in different ways and modalities, a factor our participants were highly aware of. Their suggestions included links to other resources, video clips, narrations, decision trees, and making use of the website as a collecting container for all relevant material.

The need for communication has another quality, and requires a higher degree of involvement with other people. This support need could be subdivided into *sharing experiences*, *advice and feedback* and *befriending*. These three sub-themes mirror different types of communication: the first two have the aim of addressing support needs, while the third transcends to a personal level. The communication of thoughts and feelings is the basis of all kinds of psychological support and treatment, and having the opportunity to do this is probably a prerequisite for preserving psychological wellbeing. This support need is one of the most frequently reported needs in other studies, often expressed as the need to have “someone to talk to” [1,5,11]. It could be argued that this theme is also about knowledge, as knowledge is certainly constructed in the meetings, but we claim that the core component is communication/contact. Communication on the web has clear advantages: discussions on forum boards do not disappear, but are left for others to share. Furthermore, communication can be made without anyone knowing who you are, thus diminishing shame. However, this type of communication is also restrictive, which became evident in the befriending sub-theme. Here, we saw the wish for transcendence from the forum board via personal e-mail contact to

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a real-life meeting. Therefore, if real-life meetings are made possible this restricted communication can also work as a gateway to real-life contact.

The theme covering the need for outside involvement reveals other types of needs, and the degree of involvement is increased yet further. If knowledge corresponds to thinking and communication to talking, then outside involvement corresponds to doing. Outside involvement is about the adult society acting, and about YCs making them act. This theme can be subdivided into *acute relief*, *structured help*, and *health care commitments*. The sub-themes correspond to different levels of outside involvement from a personal to a political level, from the need for “someone to take over” via the need for more persistent interventions, to the need for “thought-out and caring health care”. As this theme is about the need for real-life action, the use of a website to support these needs may not be obvious at a first glance.

The support needs that emerged in the present study have been reported in other studies [1,5,28], though the salience of these needs seems to vary depending on, for example, age and life context.

Similar support needs as those found in the present study have been described in studies on web-based support focusing on young people in other types of situations: information and communication with professionals [20], provision of self-management strategies and meaningful social support [20]. Visually appealing and interactive, media-based interface technologies have been both requested [20] and shown as an effective teaching tool [21] and also a means of reaching specific target groups [18,20]. It has been indicated that the most frequently used types of web support are sharing experiences, seeking information, providing/seeking support and advice, and seeking contact with others outside the website, for real-life meetings and exchange of email addresses [18]. Barriers for use of web-based support can be technical, for example passwords, but also psychological, for example

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reluctance to identify with the reason for the support need [19]. To take account of effects of anonymity on information sharing in online groups has been proven important in earlier research [29] and was further explored in a recent study [30].

Although support needs differ between different groups of youths, there is a common ground of needs comprised in the themes of knowledge and communication. There is also a common wish for visualised content.

In a recent report [28], YCs 16–24 years of age were asked about their view of web-based support. Only a few of them were interested, with most preferring real-life support. We find this most interesting, and will return to this finding as it is to some degree congruent with our participants' statement that "the Internet is not enough". We will also try to outline the implications for a web-based support system, one of whose aims will be to support befriending and ease contact with resources related to outside involvement (ROIs), meaning health care, social care, the police, school and other societal resources that have the possibility or authority to act on the YC's situation.

### *4.2 Implications of results*

In this section, we discuss the implications of our results for the design of a web-based support system directed at YCs. We will not address financial or security aspects, though both would have to be taken into account in practice, as our aim is to concentrate on how to meet support needs.

The support needs in the knowledge theme and most of the needs in the communication theme can potentially be met within the framework of web 2.0 technology [31]. However, it is important to consider certain elements of design [18,20,21,30] and

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barriers to use [19]. To extend the support one step further we must also consider the role that web-based support can play when it comes to the need for real-life contacts and action. Our interviewees expressed a desire that contacts initially made on a forum board could later become more personal, and one-to-one. There was also a wish that such contacts could become real (the *befriending* sub-theme). The needs grouped within the theme of outside involvement were predominantly those concerning real-life contacts. This theme included aspects which required the adult world to act on the situation of YCs. It revealed that there is a need to improve the ROIs' understanding of YCs' needs and their situation, in order to apply their expertise and achieve better communication between all parties close to the PM.

One implication of our results is that a web-based support system for YCs should be at least partly anchored in geographical areas. A localised forum board makes it possible for users in virtual contact to also connect in real life, while a localised website is better able to draw attention to and facilitate contact with the ROIs in the place where the YCs live. While the shaping of a localised forum board is largely a technical issue (although security and anonymity issues do need careful consideration), the facilitation of contact with ROIs is more complex. Several research articles indicate that trust could be an important factor in YCs' relationships with others. Time is needed to develop trust and overcome feelings of betrayal [32], and the reluctance of YCs to speak about their situation can be a barrier to receiving help [16]. Lack of trust in health care or social care has also been reported [1,33]. In our material, the lack of trust in health care was the most obvious aspect, but the reluctance of the YCs to talk about their situation was also clear. Some research indicates that YCs may need someone who they feel can represent them and act in their interests [5,1]. To help YCs make contact with ROIs, we need a support system that does something for them; a support system that can help in developing trust. This of course needs human input – a dedicated editorial staff that

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can represent YCs and explore relevant ROIs. We believe that it is important for this staff to have continuous communication with local ROIs and to mediate this in the web-based support system. This will increase relevant knowledge about these resources and help to make them more visible, transparent, and familiar to the YCs. Conversely, this could also help the ROIs gain a better understanding of the lives of YCs. To also meet and talk to the YCs using the web support system would of course be optimal; however, this must never be pushed, but rather, be an option. The YCs' increased familiarity with ROIs and the improved insight that the ROIs would have into their life situation can make it easier for the YCs to take the step and make contact when this is needed, and improve understanding and interaction between the parties.

Paradoxically, the recent finding [28] that young adult carers are not generally interested in web-based support, but rather, in personal contact, supports the suggestions outlined above. The answer to the question of the usability of a web-based support system is dependent on what those being asked think this support can be used for. It is not obvious that web-based support actually has the potential to connect peers in real life and also facilitate contact with, for example, the health care system.

Human resources may be needed as mediators in different types of electronic support systems for various reasons. Recent projects have concluded that telecare for older people does not suit all potential users and does not replace (local) care networks; furthermore, telecare has been shown to be dependent on mediating (local) human resources and trust [34,35]. In addition, human mediation has been described as crucial in psychotherapy via the web [36].

### *4.3 Discussion of methods*

Fewer participants than expected declared their interest in the study, even though steps had been taken to increase participation, for example in the wording of the advertisements, by offering the possibility to choose the type of interview, and by not initially insisting on personal contact with those who expressed interest in the study. Problems with reaching YCs have been reported in other studies. There seems to be a general wish among YCs to keep their care role secret for a number of reasons: not betraying the PM, the PM's desire to keep the situation a secret, own shame, stigma, and associated stigma [6,16,33]. Research has also shown that the ability to talk and reflect on caring experiences is generally good but dependent on trustful relations [32], a factor that probably played a part in the seemingly low interest in participating in the study.

The recruitment problems may signify that the YCs who participated in the present study were unusually aware of their situation and their feelings and position regarding MI. If so, then while their representativeness may be questioned, this also means that they had perspective on their situation and could talk about it in an informed way. The fact that they took the risk and talked about their experiences suggests that they had already gained and internalised a sense of trust. Although it is not possible to say whether our participants differed from the general group of youths in similar situations, as a whole they showed a diversified background representing different care situations and types of relationships. Several participants had long-term experience of being close to and supporting someone with MI.

As stated in the Methods section, we differentiated between expressed needs and inferred needs. Literature relating to the design of technical artefacts [37,38] such as websites, stresses that it is necessary to know about the world of the user, in regard to the relevant area of

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interest, in order to know his or her needs. This knowledge can be gathered in a number of ways, from surveys, to interviews and contextual inquiries (which implies both interviews and an ethnographic methodology) [38]. As a complement to the expressed needs we made inferences of needs embedded in the context as described in the Methods section. This added some important needs that were not otherwise stated.

Most of the needs that were inferred were also clearly expressed and therefore were not added in domain three as a result. There was, however, a striking absence of expressed needs of self-care and self-protection. While the participants did talk about taking precautions and getting help the focus was very often on the PM, and their own well-being was secondary.

### **5. Conclusions**

A website has the potential to meet needs of knowledge and communication, which may be improved if taking design issues [18,20,21,30] and barriers to use [19] into account. For YCs, learning about different aspects of their own situation, sharing experiences, and getting advice may be valuable tools to survive everyday life. Round-the-clock availability and the possibility to be anonymous can ease use and contact. Virtual contact may, however, not be enough. Several YCs interviewed in this study also wanted to get in touch in real life, and they sometimes also needed health care or social care to offer direct help. Although web-based support cannot deal with such needs, it can facilitate them. We have outlined a concept of web-based support system as an integrated part of the whole context and not just as a standalone application. In this way, it could serve as a flexible tool in the support of YCs' needs and a way to increase understanding and interaction between the parties involved. It is not possible to say if the results of this study are transferable to a larger population or to other

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groups of YC's, although existing research may indicate that. Further research could corroborate the results.

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### **References**

- [1] Becker S, editor. Young Carers in Europe: an Exploratory Cross-National Study in Britain, France, Sweden and Germany. Leicestershire: Young Carers Research Group; 1995.
- [2] Becker S. Global perspectives on children's unpaid care giving in the family: research and policy on "Young Carers" in the UK, Australia, the USA and sub-Saharan Africa. *Global Social Policy* 2007;7:23–50.
- [3] Earley LH, Cushway D, Cassidy T. Children's perceptions and experiences of care giving: a focus group study. *Counselling Psychology Quarterly* 2007;20:69–80.
- [4] Aldridge J. The experience of children living with and caring for parents with mental illness. *Child Abuse Review* 2006;15:79–88.
- [5] Cooklin A. Children as carers of parents with mental illness. *Psychiatry* 2006;5:32–35.
- [6] Butler AH, Astbury G. The caring child: an evaluative case study of the Cornwall Young Carers Project. *Children & Society* 2005;19:292–303.
- [7] Bolas H, Van Wersch A, Flynn D. The wellbeing of young people who care for a



## WEB BASED SUPPORT SYSTEM FOR YOUNG CARERS

dependent relative: an interpretative phenomenological analysis. *Psychology & Health* 2007;22:829–850.

[8] Dearden C, Becker S. Growing up Caring: Vulnerability and Transition to Adulthood – Young Carers’ Experiences. Leicester: Joseph Rowntree Foundation; 2000.

[9] Socialstyrelsen. Barn till psykiskt sjuka föräldrar. (*Children of mentally ill parents*) [in Swedish]. SoS Rapport 1999-3-11. Stockholm: Socialstyrelsen; 1999.

[10] Granath K. “Det var så mycket jag inte förstod ...” – en intervjuundersökning med vuxna barn till psykiskt sjuka föräldrar. (*“There was so much I didn’t understand ...” – an interview study with grown-up children of mentally ill parents*) [in Swedish]. Sköndalsinstitutets arbetsrapportserie 1997. Stockholm: Sköndalsinstitutet; 1997.

[11] Östman M. Interviews with children of persons with a severe mental illness – investigating their everyday situation. *Nordic Journal of Psychiatry* 2008;62:354–359.

[12] Hedman-Ahlström B. Major depression and family life – the family’s way of living with a long-term illness [dissertation]. Gothenburg, Sweden: Sahlgrenska Academy, University of Gothenburg; 2009.

[13] Nationell psykiatrisamordning och socialstyrelsen. Nationell kartläggning – stöd till barn vars föräldrar har kontakt med psykiatri. (*National survey – support for children of parents in contact with psychiatrists*) [in Swedish]. Delrapport till “Barn till föräldrar med psykisk sjukdom”; 2007. Available: <http://www.socialstyrelsen.se/> via the Internet. Accessed 2010 Sept 22.

[14] Svensk Författningssamling (SFS). Hälso- och sjukvårdslagen, §2g. [Health care law, §2g] Stockholm, Sweden: Riksdagen; 1982:763.

[15] Feenberg AL, Licht JM, Kane KP, Moran K, Smith RA. The online patient meeting.

## WEB BASED SUPPORT SYSTEM FOR YOUNG CARERS

Journal of the Neurological Sciences 1996;139:129–131.

[16] Banks P, Cogan N, Riddell S. Does the covert nature of caring prohibit the development of effective services for young carers? British Journal of Guidance & Counselling 2002;30:229–246.

[17] Gray B, Robinson C, Seddon D. Invisible children: young carers of parents with mental health problems – the perspectives of professionals. Child and Adolescent Mental Health 2007;13:169–172.

[18] Giesbers J, Verdonck-de Leeuw IM, van Zuuren FJ, Kleverlaan N, van der Linden MH. Coping with parental cancer: web-based peer support in children. Psycho-Oncology 2010;19:887-892.

[19] Nordfeldt S, Hanberger L, Berterö C. Patient and parent views on a Web 2.0 diabetes portal-The management tool, the generator, and the gatekeeper: qualitative study. Journal of Medical Internet Research 2010;12:e17.

[20] Stinson JN, Toomey PC, Stevens BJ, Kagan S, Duffy CM, Huber A et al. Asking the experts: exploring the self-management needs of adolescents with arthritis. Arthritis & Rheumatism 2008;59:65-72.

[21] Pacifiki C, White L, Cummings K, Nelson C. Vstreet.com: a web-based community for at-risk teens. Child Welfare 2005;84:25-46.

[22] Statens offentliga utredningar (SOU). Ungdomar, stress och psykisk ohälsa: analys och förslag till åtgärder. (*Youth, Stress and Mental Health Problems: Analysis and Suggestions for Action*) [in Swedish]. Stockholm: Fritzes; 2006:77.

[23] Socialstyrelsen. Folkhälsorapport 2009. (*Public Health Report 2009*) [in Swedish] SoS-rapport 2009-126-71. Stockholm: Socialstyrelsen; 2009.

## WEB BASED SUPPORT SYSTEM FOR YOUNG CARERS

- [24] World Internet Institute. Svenskarna och internet 2008. (*The Swedes and the Internet 2008*) [in Swedish]. Hudiksvall: World Internet Institute; 2009.
- [25] Kummervold PE, Gammon D, Bergvik S, Johnsen J-AK, Hasvold T, Rosenvinge JH. Social support in a wired world: use of online mental health forums in Norway. *Nordic Journal of Psychiatry* 2002;56:59–65.
- [26] Krippendorff K. *Content Analysis: an Introduction to its Methodology*. Thousand Oaks, CA: Sage Publications; 2004.
- [27] Science Plus - Software for science [Internet]. Atlas.ti - [cited 2010 Jun 21]; Available from: <http://www.scienceplus.nl/atlasti/>
- [28] Becker S, Becker F. *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–22*. London: The Princess Royal Trust for Carers; 2008.
- [29] Tanis M, Postmes T. Two faces of anonymity: paradoxical effects of cues to identity in CMC. *Computers in Human Behaviour* 2007;23:955-970.
- [30] Wodzicki K, Schwammlein E, Cress U, Kimmerle J. Does the Type of Anonymity Matter? The Impact of Visualization on Information Sharing in Online Groups. *Cyberpsychology, Behavior, and Social Networking* 2010; doi:10.1089/cyber.2009.0383.
- [31] Lupiáñez-Villanueva F, Mayer MÁ, Torrent J. Opportunities and challenges of Web 2.0 within the health care systems: an empirical exploration. *Informatics for Health and Social Care* 2009;34:117–126.
- [32] Grant G, Repper J, Nolan M. Young people supporting parents with mental health problems: experiences of assessment and support. *Health and Social Care in the Community* 2008;16: 271–281.

## WEB BASED SUPPORT SYSTEM FOR YOUNG CARERS

- [33] Thomas N, Stainton T, Jackson S, Cheung WY, Doubtfire S, Webb A. “Your friends don’t understand” – invisibility and unmet need in the lives of “young carers”. *Child and Family Social Work* 2003;8:35–46.
- [34] Moser I, Thygesen H. Telecare for the elderly living at home: new care arrangements, practices, relations and definitions. The European Association for the Study of Science and Technology (EASST) conference; Practicing Science and Technology, Performing the Social, 2010 September 2-4; Trento, Italy; 2010 p. 533 (oral presentation).
- [35] Conci M, Chiara L. Not every patient is 2.0: importance of mediation for accessible healthcare services. The European Association for the Study of Science and Technology (EASST) conference; Practicing Science and Technology, Performing the Social, 2010 September 2-4; Trento, Italy; 2010 p. 534 (oral presentation).
- [36] Andersson G, Carlbring P, Berger T, Almlöv J, Cuijpers P. What makes internet therapy work? *Cognitive Behaviour Therapy* 2009;38:55-60
- [37] Sharp H, Preece J, Rogers Y. *Interaction Design: Beyond Human-Computer Interaction*. New York, NY: John Wiley & Sons, Inc; 2002.
- [38] Kuniavsky M. *Observing the User Experience*. San Francisco, CA: Morgan Kaufmann Publishers; 2003.

Table I. Data on participants (N=12) and the person(s) with mental illness (PM) whom they were close to and supported.

Participants	Person(s) mentioned as supported
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Participants	Years of age	Gender	Years as carer	Type of interview	Parent	Sibling	Friend	Relative	Girl/Boy- friend	The supported person(s) type of problems
1	20	F	5	Ftf	1	1	3			1) depression and anxiety, 2) social isolation, 3) depression
2	17	F	4	Ftf			3			1) destructive and self destructive behaviour, 2) bad home situation and heavily rejected by family, 3) emotionally "turned off" and has gone nocturnal
3	24	M	8	Ftf			2	1		1) severe crisis and hypomanic, 2) identity crisis, 3) development of anorexia nervosa
4	20	F	S	Fg	1					1) bi-polar disorder
5	21	F	4	Fg		1				1) depressed, unrealistic plans and symptoms resembling borderline personality disorder
6	18	F	18	Fg	2		S		1	1) extreme agoraphobic symptoms, 2) alcoholism, 3) anxiety, 4) depression and suicidal thoughts
7	22	M	3-10	Fg			1		1	1) borderline diagnosis, inability to manage everyday life, 2) lack of self-confidence and described as narcissistic
8	20	F	7	T		1				1) panic attacks and destructive relations
9	24	M	6	Ftf			S		2	1) bi-polar disorder, 2) suicidal thoughts or destructive behaviour, 3) depression and panic anxiety, 4) depression
10	21	F	2-3	T			2			1) extreme suicidal thoughts, 2) depression and manipulative behaviour
11	24	F	7	T	1					1) depression due to exhaustion
12	25	F	25	T	1	1				1) bi-polar disorder, 2) manic depressive disorder

F=female, M=male, Ftf=face-to-face interview, Fg=focus group interview, T=telephone interview, S=several.