

Caring Situation and Provision of Web-based Support for
Young Persons who Support Family Members
or Close Friends with Mental Illness

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UNIVERSITY OF GOTHENBURG

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Caring Situation and Provision of Web-based Support for Young Persons who Support
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*To my parents Jaffar and Bushra, who gave me all their love and care
and the confidence to know that I can reach any goal I set my mind to.*

ABSTRACT

Changes in psychiatric health care and increased reliance on outpatient care have resulted in the transfer of responsibility for care from psychiatric services to social networks. Young persons therefore often take responsibility during their own sensitive phase of emerging adulthood for the care of a loved one who suffers from mental illness.

The overall aim of this study was to learn how young persons who provide care and support to a person with mental illness handle their everyday lives. This study also aimed to evaluate web-based versus folder support for these young informal carers. The papers in this thesis use qualitative descriptive (I), comparative (II), mixed methods (III), and experimental (IV) design approaches. Participants were recruited twice: first, 12 participants were recruited for the qualitative papers and interviewed; then 241 participants were included in the interventions and sent self-administered questionnaires by email or the regular postal service at the start of the intervention (T_1), after 4 months (T_2), and after 8 months (T_3) during 2010 and 2011. Young informal carers (YIC) managed their everyday lives and unexpected stressors from their perceived responsibility for the supported person by relying on their own abilities and their social networks and by maintaining a constant state of readiness in case something should happen to the supported person. Supporting a person in the family can have higher positive subjective value than supporting a friend. Although friends perceived that they received more support. They often did not share their situation with others and felt that others did not understand what they were going through; even when YIC did share their burden with their social networks, they felt either that they were ignored or that others did not know how to act or what to say. YIC often experienced a lack of appropriate, available, and serious professional support. They thought that support from professionals might improve their caring situation and that it might ease their burden if the person with mental illness had more professional care and support.

Baseline stress levels were high in both intervention groups (web-based support versus informational folder), but decreased in the folder group. The folder group showed more improvement in their caring situation than the web group, and improvements in general self-efficacy, well-being, and quality of life. The web group also showed improved well-being. Non-significant differences between the groups indicate that each intervention could be useful depending upon the individual's preference. This highlights the importance of adopting a person-centred approach to offer young persons the appropriate support.

Keywords: informal carers, family, friends, mental health, support, young persons

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LIST OF ORIGINAL PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I Ali, L., Hedman Ahlström, B., Krevers, B., & Skärsäter, I. (2012). Daily life for young adults who care for a person with mental illness: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 7, 610-617.
- II Ali, L., Krevers, B., Skärsäter, I. Caring situation, health, self-efficacy, and stress in young informal carers of family and friends with mental illness. *Resubmitted*
- III Ali, L., Hedman Ahlström, B., Krevers, B., Sjöström, N., Skärsäter, I. Support for young informal carers of persons with mental illness: a mixed-method study. *Accepted in Issues of Mental Health Nursing*.
- IV Ali, L., Krevers, B., Sjöström, N., Skärsäter, I. Effectiveness of web-based versus folder support interventions for young informal carers of persons with mental illness: a randomized controlled trial. *Submitted*

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ABBREVIATIONS

BRIS	Barnens Rätt I Samhället (Childrens Rights in Society)
CONSORT	Consolidated Standards of Reporting Trials
COPE-index	Carers of Older People in Europe Index
ITT	Intention to Treat
GSE	General Self-Efficacy
PD	Participatory Design
PMI	Person with Mental Illness
PP	Per Protocol
PSS	Perceived Stress Scale
PsYoungSupport	Psychiatry Young Support
WHO	World Health Organization
WHO-QoL-5	World Health Organization Quality of Life Assessment
YIC	Young Informal Carer(s)

PREFACE

For the past four and half years I have made one of the most developmental journeys of my life. I have travelled in the world of research science and I have learned that there truly is a world beyond my own view. I have always thought of myself as a person who is curious and I have been eager to enter completely new and unknown areas of life just to find out about them; this feature of mine has been an advantage in research. My doctoral candidate position in the research project was a great change from my past 10 years as a clinician in psychiatric departments. I went from meeting patients on a daily basis to trying to understand the families' and friends perspectives using research methods and analysing data. I felt quite lost and I expressed that to my supervisors, who told me that I would discover by the end that this journey is like walking in the woods on a foggy day, struggling to find my way out, and emerging from the woods just as the mist fades away. When I turn around I see the path I have walked, and I discover I have taken the long way around instead of many short cuts that I could have walked. I can truly tell you now; this journey has been exactly like that! The difference is that now I have learned the road and next time it will be much easier to find my way out...

Cover illustration: Design by Maryam Aljaderi

INTRODUCTION

Young persons are exposed to a great deal of psychosocial stress in their development from the late teens into their 20s, with the years from 18 to 25 recognized as a period of emerging adulthood (Arnett 2000, 2002, 2006). Emerging adulthood is distinguished by changes in social roles and normative expectations (Arnett 2002). In emerging adulthood the dependency of childhood is left behind, yet the responsibilities and norms associated with being an adult still lie ahead. Being responsible for caring for a person with mental illness (PMI) could make this developmental phase even more stressful. Young informal carers (YIC) can be defined as persons aged 16 to 25 who provide or intend to provide care, assistance, or support to a person who is disabled or suffers from a long-term illness, mental health problem, or other condition requiring care and support. YIC regularly carry out tasks on a level of responsibility usually associated that of an adult (Becker 2007).

This thesis will provide an understanding of the daily life situation of the YIC as related to the health care science of mental health nursing. It can be a difficult situation for young persons to care for and support a person close to them who suffers from mental illness such as threatened suicide, depression, or anxiety (Grant et al., 2008). Young persons, who are largely unidentified by health care organisations, often take great responsibility for their loved ones, but knowledge about their situation and how to support them in their role as YIC is lacking.

Young persons

The end of adolescence and the phase of emerging adulthood is a sensitive time. It is when the basis of a young person's identity is consolidated and when friends and well-functioning parents are of great importance (Ericson 1950; Arnett 2000).

According to Ericson's theory of life's eight stages (1950), people struggle from the age of 18 to 40 to belong, to feel accepted and affirmed in society, and conversely to develop as individuals is in itself a dilemma apart from other distractions and confusions, such as trying to find the right education or career path, which most persons experience in late adolescence. Adolescence now begins earlier than it did a century ago, because in industrialized countries puberty begins much earlier, likely due to changes in nutrition and health care. Adolescence also now ends much later as adulthood is postponed into at least the mid-20s (Arnett 2000). According to Arnett this extended post-puberty period is neither adolescence nor adulthood. Because of this prolonged phase of adolescence, the ages from 18 to 25 could be labelled as emerging adulthood instead of young adulthood. The difference between being 18 to 25 years old and being 25 to 30 is that adulthood is more likely to be reached in the later 20s rather than in the early 20's; most persons in aged 18 to 25 would not consider themselves adults (Arnett, 2002). This extended development allows young persons a longer time to explore the independent role typical of young persons in industrialized societies (Arnett 2000, 2002, 2006). Eighteen is a marker of the end of adolescence and the beginning of emerging adulthood, because it is at that age when most young person's graduate from

secondary school, move out of their parents' home, and struggle to attain the markers of adulthood, such as entering and completing university and eventually getting a job (Arnett 2002, Phillips et al., 2005, Frisé et al., 2011, Wängqvist et al., 2011). At the same time, young persons need to form close relationships, find a partner, and start a family. According to Arnett, no significant transition takes place at the end of adolescence since "emerging adulthood" is not something a person becomes; emerging adulthood is a developmental period in which nothing is normative. However, this does not agree with Meleis (2010), whose theory of transition from childhood to adolescence posits a period in life that is significantly associated with health problems, both mental and physical. Meleis argues that changes in a person's role are associated with changed behaviour in one or more persons in that person's social circle, such as parents, children, or close friends, those changes may force other changes reciprocally. Such reciprocal change according to Meleis should be taken into consideration, for example when planning an intervention for patients' significant others. Research show that providing care and support to a PMI while in the phase of emerging adulthood can lead to consequences later in the YIC's life. These young carers often do not complete their education, which leads to not being able to get a job; unemployment is commonly followed by a life of poverty and alienation (Dearden 2000).

Young persons and mental health

About 25% of all persons and their families are affected by mental illness, which results in significant stress, burden, and decreased quality of life and well-being among young people (Walton-Moss et al., 2005, Patel et al, 2007, Grant et al., 2008, WHO 2010, Swedish National Board of Welfare 2011, 2013). There is an increased mental health problem among young persons in Sweden (Swedish National Board of Welfare, 2010, 2011, 2013) and alarming figures show rising curves in mental illness since the 1990's. Mental illness is increasing especially among young women (ages 16–24) in Sweden. Suicide among young women has increased dramatically, and 25% of all 16- to 24-year-old women and men who died committed suicide, this number have been unchanged for the past decade. There are also increasing numbers of young persons who receive care for mental health issues such as stress, worry, uneasiness, or anxiety (Swedish National Board of Welfare, 2011, Swedish National Institute of Public Health, 2013).

Annual national reports show decreasing resources for the psychiatric health care system in Sweden, which is one reason Swedish psychiatric care services have such long waiting lists for PMI (Swedish National Board of Welfare, 2010, 2011). This result in care and support for the PMI being transferred to their next of kin, with consequences for their social network, such as family and close friends (Moore et al., 2007, Stjernswärd et al. 2008, Van Wijgaarden et al., 2004, 2009). YIC are given no choice other than to take on involuntary responsibilities, relying on their own ability to manage their everyday life. Young persons have individual capacities and vulnerabilities; this is why each young person's self-esteem is so individual. All, however, depend upon their own belief in their ability to handle difficult situations, and this can be an essential resource for young persons (Bandura 1997) who live close to persons with mental illness. Important to self-efficacy are enactive mastery experiences, which, if

positive, will generate high overall self-efficacy. Observation of others succeeding in certain situations will also increase self-efficacy, especially if they can relate to the role model's conditions. Significant others can persuade people that they can manage a situation, which makes them put more energy into the project and be more likely to succeed (Bandura 1997). Lindgren et al. (2010), whose study included healthy adolescent school girls involved in an empowerment-based exercise intervention, resulted in increasing the girls' self-efficacy. It has been reported that family caregivers with high expectations of self-efficacy are less vulnerable to stress than those with lower expectations (Contador et al., 2012). WHO (2010) suggests that professionals working with young person's health should not only address health problems directly, but also consider the families' influence in supporting the development of health-promoting behaviours.

Care and support

Caring has been considered to begin with being present and being open to compassion, mercy, gentleness, loving-kindness, and equanimity towards oneself before being able to offer compassionate care to others (Watson 2008). Building a trustful relationship is central to care and involves real engagement, commitment, and truly seeing the other as an individual, having a humble attitude, and trying to understand the other person's life-world (Mayerhoff, 1971). Mayerhoff (1971) also describes the significant other as a person who is cared for, who enables another person to feel complete, and who creates the conditions for continued personal growth. Supporting another person's growth leads to that person taking charge of his or her situation and taking responsibility for their own life and need for care. Learning, included in growing, leads to the re-creation of a person's own beliefs by the integration of values and ideals based on the person's individual experiences and ideas (Mayerhoff 1971). In this thesis the YIC could have that type of relationship with either a family member or a friend who suffers from mental illness.

Informal care

In this thesis I use the term "informal care", rather than caregiving, which mainly refers to caregiving provided by the family. Informal care is a wider term that includes friends, relatives, and others care for a PMI they know socially (Parker, 1994). It has been recognized that informal care consists of emotional help, such as keeping a person company, or keeping an eye on someone, as well as providing practical assistance (Horowitz, 1985, Parker, 1994, Sørensen et al., 2002). The difference between informal care and formal care is that formal care is provided by social- and health-care systems and by professionals, while informal care may be provided by anyone close to the person who is disabled or suffering from an illness (Nolan et al., 1996; Van Hautven et al., 2004). There has been on-going discussion about whether or not informal care is a substitute for formal care. When highly qualified and specialised care is required to restore health, informal care is unlikely to be adequate. It is well, or even better, suited than formal care, however, for assistance in the activities in daily life living (Van Hautven et al., 2004). These were for adults providing informal care to the elderly; there is still a lack of research on young persons who provide informal care to young persons with mental illness who might not be family members.

Social support for young informal carers

Being an adult informal carer of a PMI often means being alienated from professional care (Ewertzon et al., 2010). Studies indicate that relatives need support from professionals or social support from persons with some experience of being an informal carer (Östman et al., 2000; Östman et al., 2005, Ewertzon et al., 2010; Weimand et al., 2010, Hastrup et al., 2011). Having a close relationship with a PMI have substantial consequences on the health of YIC (Thomas et al., 2003, Walton-Moss et al., 2005, van Wijngaarden 2004, 2009). Some YIC have to change their daily routines to be able to take care of the PMI (Butler et al., 2005, Hedman Ahlström et al., 2007, 2009), which indicates that YIC take on a burden when they take on care. It is not easy to identify this target group because they need encouragement to step out of their invisible roles (Grant et al., 2008). YICs are not used to receiving attention from professionals, because such attention has usually been on the PMI (Aldridge 2006, Ewertzon et al., 2011). However, a few studies have focused on the situation of YIC (Aldridge 2006; Grant et al., 2008).

It is known that social support plays a vital role in everyday life; social support contributes to improved mental and physical health (Albrecht et al. 2003) but receiving care is not the same as receiving social support (Finfgeld-Connett 2007). Caring is provided by specialist nurses, while social support is provided primarily by family, friends, neighbours, and other acquaintances (Finfgeld-Connett 2007). Social support falls into two categories: emotional and instrumental. Emotional support aims to meet needs related to stressors such as low self-esteem, sadness, frustration, anger, anxiety, uncertainty, and loneliness (Gilliland et al., 2001; Green et al. 2002; Finfgeld-Connett 2005). House et al. (1988) defined receiving social support as obtaining emotional concern, instrumental aid, information, and appraisal through the social network. It is obvious that care and support may have similarities; however, even though there is some research comparing care and social support in recipients who are adults, there is still a lack of research on the combination of care and social support for YICs of PMIs. With the development of social media, social support through the web is integrated with most people's daily life contact with their families, friends, and even strangers (Findahl 2012). Nurses and other health care personnel should take advantage of this progress to facilitate their contact with persons in need.

Nursing informatics

Nursing informatics is a combination of computer-, information-, and nursing science, which assists in the processing of nursing data, information, and knowledge support, as well as in the delivery of nursing care in everyday practice for nurses (Graves et al., 1989, Staggers et al., 2009). Nursing informatics study the structuring and processing of nursing information to build supportive systems for persons to improve their health, which is its main purpose (Graves et al., 1989, Staggers et al., 2009). Previous research shows that web-based interventions for improving health and quality of life of persons who have long-term illness or other dysfunctions, are feasible and should be considered effective (Del Pozo-Cruz et al., 2012, Dang et al., 2012, Van Rosmalen-Nooijens et al., 2013). It has also been shown that online cognitive behavioural treat-

ment may be just as effective in routine practice as it is in clinical trials (Andersson 2009, Ruwaard et al., 2012).

The possibilities of eHealth for young informal carers

Access to the internet in Sweden is high; 89% of the Swedish population over the age of 16 has daily access to the web in their homes, and 81% use the web every day. Over half of all web users, regardless of age, search the web for health-related issues (Jiménez-Pernett 2010, Findahl 2012). The most frequent key words that young person's search for are "depression", "anxiety", "stress", and "mental health issues" (Fox et al., 2007, Fox, 2011, Ayers et al., 2013). The most common reason for searching the web is "concern for someone else's health" (Fox et al., 2002, 2012, Rice 2006, AlGhami et al., 2012). People of all ages who use the web need knowledge about diseases, treatments, and coping strategies, and social support through chat pages, e-mail lists, or self-help sites (Ferguson et al., 2002, Morahan-Martin 2004, Josefsson 2005, Reavley et al., 2011, Findahl 2012, AlGhami et al., 2012). Having family members with mental health problems is associated with searching the web for information about mental health issues (Reavley et al., 2011, Fox, 2012). The use of the web was lower than the use of informal or interpersonal sources, such as friends (Gould et al., 2002, Elf et al., 2011). This is supported by other studies with users of different ages (Findahl 2012). There is a risk of over-exposure to information on the web that can cause mental symptoms, irritation, frustration, and disempowerment (Henwood et al., 2002, Thomée et al., 2007, 2010), yet there is a need to develop well-promoted strategies that are appealing and reduce barriers to seeking help for those in need (Nicholas 2010). Gould et al. (2012) found that young persons have a negative opinion about mental health services on the web that might be a barrier to their seeking help when in need. Research shows that even though young person's use the web frequently as a source of help, it is still not enough (Elf et al. 2011).

The internet has developed rapidly and is a modern tool for health-related issues (Välimäki et al., 2007, Horgan et al., 2010, Jiménez-Pernett 2010, Kurki et al., 2013). Research carried out in Sweden (Stjernswärd et al., 2007) shows that more can be done on the web to reach out to a target group in need of support; web sites currently offer only one category of information when they should offer several categories by addressing important issues and reaching out to all who are in need of health-related online support. As the internet becomes more and more fundamental to young person's lives, eHealth becomes an expected technology, especially for providing support to YIC supporting a PMI (Findahl 2012, Horgan et al., 2010; Jiménez-Pernett 2010). Eysenbach et al. (2002) conducted a systematic review of the quality of the health-related information online and concluded that a large amount (70%) of what is provided online was not reliable and was reported by users to be poor quality. Powell et al. (2003) and Gallagher et al. (2008) found that people increasingly searched the web for mental health information without seeking help from mental health care services. This increasing reliance on the web, coupled with a lack of online support well-suited to YIC and their willingness to search online for mental health information demonstrate the importance of conducting an eHealth for young persons (Horgan et al., 2010).

RATIONALE OF THE STUDY

The Swedish mental health care system has transferred many of its services to open care, increasing the strain and burden on the PMI's next of kin and turning their social networks into lifelines. Friendships are important to young person's lives and well-being, because relationships are an important part of their development into adulthood. Knowledge about how young persons who are close to, and care for, a PMI (family member or friend) manage their everyday lives is sparse. Caring for a PMI means accepting a burden and exposing oneself to stress. One way to alleviate this group's burden could be through support and information about how best to handle their situation, how to live with both the challenges of their developmental stage and continue with school and leisure activities while providing care and support for the PMI. There is also a lack of research on friends as informal carers, as research in this field has mainly focused on the situation of informal carers in the family. Both groups should be investigated further. We assumed that YIC supporting a family member would likely have a different life situation than a YIC supporting a friend, because they would have different options, different support systems, and possibly different ways of benefitting from support interventions.

AIMS OF THE THESIS

The overall aim of this thesis was to gain knowledge of how young persons who provide care and support to a person with mental illness handle their everyday life. This study also aimed to evaluate web-based versus folder support interventions for young persons who were first degree relatives or close friends of persons with mental illness.

This thesis comprises four papers with the following aims:

- | | |
|-----------|---|
| Paper I | To elucidate the daily life of young adults who cares for a person with mental illness and how these young informal carers handle their everyday life. |
| Paper II | To compare caring situation, health, self-efficacy, and stress between young informal carers who support a family member or a friend with mental illness. |
| Paper III | To elucidate the experiences of support for young informal carers of persons with mental illness, and to examine the usage of support for young informal carers of persons with mental illness. |
| Paper IV | To compare the impact of two interventions, a web-based support and a folder support, for young informal carers of persons with mental illness. The primary outcome was stress; secondary outcomes were caring situation, general self-efficacy, well-being, health, and quality of life. |

METHODS

Design

This study used a multi-method approach with both qualitative and quantitative methods. A qualitative approach makes it possible to study the subjective understanding of individuals, which refers to the tradition of interpretation (Patton 2002, p. 115). Once we understand the individuals' subjective worlds, we are at the first step of knowing the truth, the meaning and the interpretation of the source, which in qualitative research draws on the personal experiences of individuals (Munhall 2012). In quantitative research empirical evidence is gathered directly or indirectly through the senses, which are rooted in objective reality, rather than through the researchers own beliefs (Polit 2006). Qualitative and quantitative research designs complement each other as they generate different types of knowledge that are useful in health care sciences practice (Burns 2001, p. 27). Using a mixed method design requires more than simply collecting and analysing two kinds of data, however. It also involves the use of both qualitative and quantitative approaches in tandem, so that the overall strength of the study becomes greater than with only one approach (Creswell 2007).

In paper I, the design was descriptive and a qualitative method was used in order to gain a deeper understanding of the YICs' situation (Baxter 1994, Krippendorff 2004). Papers II–IV used data from a survey that evaluated a web-based intervention. In paper II a comparative and descriptive design was used to describe baseline data from the survey. Paper III had a mixed method design using a qual + QUAN á qual method from baseline data (Carr et al., 2009; Creswell et al., 2009). Paper IV was a randomized controlled design study, using the CONSORT and eCONSORT statements (Moher et al., 2001, Boutron et al., 2008, Eysenbach, 2011). The study used a pre-post comparative analysis design because it was an evaluation of the web-based and folder support intervention effects (Table 1).

The PsYoungSupport research project aimed, in cooperation with YICs as users, to investigate the design, usefulness, and effect of web-based support. In PsYoungSupport a participatory design (PD) (Spinuzzi 2005) focused on user involvement to capture persons' needs and experiences and guide the specific design according to the planned intervention (Figure 1). The method of PD was developed through involving employees in achieving a positive change at work (Gregory 2003); this involvement applied to the users. By actively involving users, it is believed that the development process will capture their tacit knowledge (Spinuzzi 2005). The core of PD is to involve the users and to capture their knowledge and expertise, which makes empowerment a core theme in the process of the design and the outcome (Spinuzzi 2005).

Data collection

For this study two different types of data collections were used. For the qualitative data (I, III) participants were recruited from the west region of Sweden, and for the survey (II, III, IV) recruitment was national. Inclusion criteria for the study were being 16–25 years old; identifying themselves as supporting a PMI, and being able to understand and communicate in Swedish.

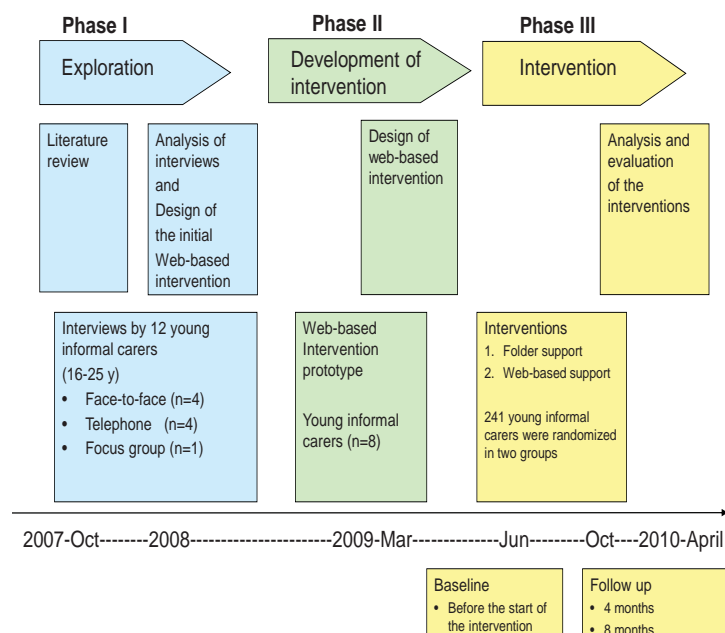


Figure 1. Design of the research study PsYoungSupport.

Table 1. Research overview of paper I-IV showing design, data collection, participants and analysis

Paper	I	II	III	IV
Design	Descriptive qualitative	Comparative and descriptive design	Mixed method qualitative, quantitative	Experimental design randomized controlled trial
Data collection	Interviews Phase I	Surveys Phase III	Interviews + Surveys Phase I + III	Surveys Phase III
Participants	Young informal carers (n=12)	Young informal carers (n=225)	Young informal carers (n=12) ^a + (n=241) ^b	Young informal carers (n=241) ^b
Analysis	Qualitative content analysis	Quantitative comparative	Descriptive and qualitative/quantitative analysis	Quantitative pre-post comparative

^aSame participant sample recruited in phase I, ^bSame participant sample recruited in phase III

Recruitment for the qualitative interviews

Young persons were recruited via advertisement in local free newspapers, leaflets distributed where young person's gather, such as libraries, youth centres, and schools. The research team also developed a special web-site (www.psyounsupport.se) for the project, which offered information about the research project, the project team members, and our aimed to recruit participants for the research study. Interested young persons could contact the researchers via this web-site, but they could also email, send a letter, or telephone.

Recruitment for the survey

Young persons were identified from the Swedish population register and contacted by telephone using a recruitment company. The goal was to include a minimum of 400 participants in the study (II, III, and IV). The recruitment company contacted young persons (n=3703) by telephone and invited them to participate in the study if they fulfilled the inclusion criteria. A total of 403 YIC agreed to participate in the study; of those 241 responded to the baseline questionnaire and were included in the study.

Participants

In paper I, 13 young persons agreed to participate in the study and to be interviewed (Table 2). After the interview, one participant who clearly did not fulfil the inclusion criterion of supporting a PMI was excluded from the study, leaving 3 men and 9 women in the study group.

Table 2. Sociodemographic characteristics of participants in paper I

Participants	n=12
Sex	
Female	9
Male	3
Age (years)	
16-20	5
20-25	7
Civil state	
Partner	3
Single/no partner	6
Married	2
Education (completed)	
Comprehensive school	4
Upper secondary school	7
Other education	1

In paper II, 225 participants were included and asked “What is your relationship to the PMI?” They were then divided into two groups: those who supported a family member (family group) (n=128) and those who supported a friend (friend group) (n=97). In the family group 42% of participants were caring for parents, 32% for siblings, 20% for a partner, and 6% for others with whom they were living with as a family member. All others were included in the friends group (Table 3).

Paper III included both the participants from the first recruitment (n=12) and the participants recruited for the intervention (n=241) (Table 4). An additional criterion to be included in the study was to answer the question about “How would you say your health is in general?”

Table 3. Sociodemographic characteristics of participants in paper II

	Family group n = 97		Friend group n = 128		Total n = 225	
	n	%	n	%		
Sex						
Female	71	73	90	70	161	72
Male	26	27	38	30	64	28
Level of Education						
Uncompleted education	0	0	2	2	2	1
Elementary school	12	12	21	16	33	14
Upper secondary school	56	58	83	65	139	62
Collage/university	29	30	22	17	51	23
Occupation^a						
Employee	33	34	27	21	60	27
University student	26	27	23	18	49	22
Other education	28	29	59	46	87	39
Unemployed	9	9	18	18	27	12
Siblings						
Yes	96	99	119	93	215	96
No	1	1	9	7	10	4
Age (years)						
Mean	20.8		19.4			

^a2 missing values**Table 4.** Sociodemographic characteristics of participants in paper III

	QUAN n = 241		QUAL n = 12	
	n	%	n	%
Age				
16–20	129	54	5	42
21–25	112	46	7	58
Sex				
Female	170	71	9	75
Male	71	29	3	25
Level of Education^a				
Incomplete education	2	1	-	-
Elementary school	33	14	4	33
Upper secondary school	130	54	7	58
Collage/university	52	22	-	-
Occupation^a				
Employee	50	21	-	-
University student	47	20	-	-
Other education	79	33	1	8
Unemployed	25	10	-	-
Age (years)				
Mean	20.1		21.3	

^a missing values

In paper IV, 403 young persons agreed to participate in the study (Table 5). Of those eligible, 241 fulfilled the inclusion criteria, which also required them to have answered the question concerning their general health in the baseline questionnaire. Twohundred fortyone participants who answered baseline questionnaire were included and randomised into two groups, the web-based support group (120) and the folder support group (121) (Figure 2). The randomization was done with the help of a statistician, and the aim was to use as homogeneous groups as possible, since a stratified sample would be used in this paper. Some participants answered the questionnaires at the first and second follow-up but did not answer in the third follow-up, even if they had received two reminders. These participants were contacted by the recruitment company and asked whether they would consent to a short telephone interview instead, which was either 5 or 20 minutes.

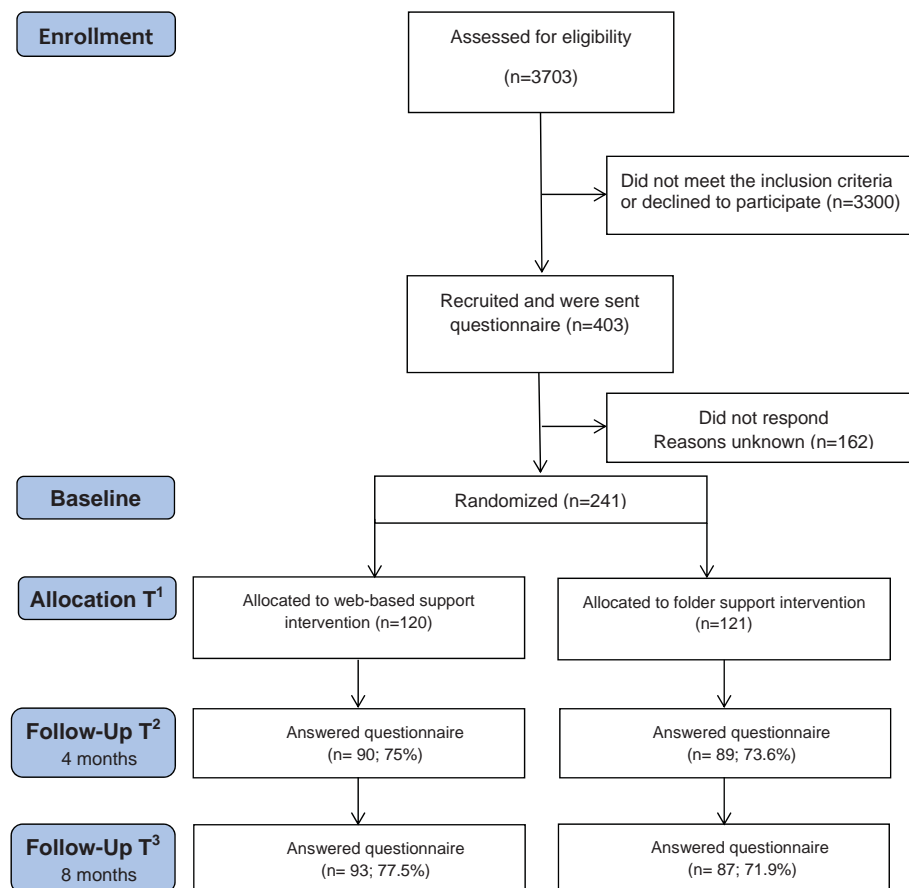


Figure 2. Flow diagram of participants randomized in the controlled trial of web-based and folder support to young informal carers at baseline, and 4 and 8 months postintervention.

Table 5. Sociodemographic characteristics of participants in paper IV

	Web based Support n = 120		Folder Support n = 121	
	n	%	n	%
Age				
16-20	65	54	64	53
21-25	56	47	56	46
Sex				
Female	87	73	83	69
Male	33	27	38	31
Level of Education^a				
Less than elementary	1	1	1	1
Elementary school	15	13	18	15
Upper secondary school	63	53	67	55
Collage/University	29	24	23	19
Occupation^a				
Employee	26	22	24	20
University student	24	20	23	19
Other education	42	35	37	31
Unemployed	10	8	15	12

^a missing values

Procedure for data collection

Interviews

All interviews for the qualitative data collection followed a semi-structured interview guide written by the research team. The questions focused on the participants' needs, considering both their experiences and their expectations about the future. They were asked to describe themselves and the persons that they provide both care and support to. Questions asked about their relationship with the person with mental illness, how it was when they became ill, how it is now, what they think about their future in an informal carer role, whether they use the web to search for information, etc. All participants could choose to be interviewed face-to-face or by telephone; they could also choose whether they wanted to participate in the focus group or not. The individual interviews were performed by two senior researchers and one PhD student and lasted for approximately 60 minutes. The focus group interview lasted for about 90 minutes and was conducted by two senior researchers and one PhD student as an observer. All interviews were tape-recorded and transcribed verbatim. The face-to-face interviews and the focus group interviews took place at a university.

Survey

The participants had a choice of answering the surveys on the web (a link was provided in their email) or on a paper version sent and returned by mail. We offered two ways of answering the questionnaire and invited survey participants to participate in the intervention in order to ensure that all participants could answer in the way that was most convenient to them. A reminder note by email or regular mail was sent out

after two weeks for those who did not answer, and another reminder was sent after four weeks. On every occasion a maximum of two reminders were sent out to participants who had not responded. All participants who completed all three questionnaires received two cinema tickets.

Assessments

For the survey, one self-administrated questionnaire was developed by the research team, comprising 65 items. The questionnaire contained both general self-rated single-answer questions and established scales.

Sociodemographic characteristics

Items about YIC sociodemographic characteristics were introduced using items such as sex, age; do you have siblings: yes/no; level of education completed: elementary school, upper secondary school, college/university; If born in Sweden: yes/No; have children yes/No; occupation employee, self-employed, academic studies, other studies, long-term sick leave, sick leave <1month, job-seeker, off duty, or parental leave. To capture the YICs engagement as informal carers one question asked about care duration in months, and others about any hindrance of their own activities because of the caring situation, their relationship to the PMI, and the geographic distance they lived from the PMI.

Health and social interactions

A single question asked, “How would you say your health is in general?” and was answered on a 5-point scale ranging from “1=excellent” to “5=bad” (Marklund 2006). Another frequently used question about quality of life asked, “How would you say your quality of life is in general?” and was also measured on a 5-point scale ranging from “1=very good” to “5=very bad” (Marklund 2006) (II and IV). One question about drug use, “Have you used any non-prescribed type of drug the past four months?” was answered yes/no (II).

To capture the YIC’s general physical condition some other commonly used questions asked about things like weekly leisure activities (yes/no) and weekly exercise activities (yes/no) (II and III). To learn about their social interactions, we asked specific questions about their social life, such as whether they had someone to share their inner thoughts with (yes/no); whether they felt alone (yes/no); and whether they had told anybody about their situation (yes/no). There were also questions asking about the YIC’s emotions such as how calm or worried about the PMIs’ situation they were, answered on a 5-point scale (“1=very calm” to “5=very worried”) and one question about the importance of their relationship to the PMI, measured on a 4-point scale (“1=greatest importance” to “5=no importance at all”) (II and III).

Stressful life events

The questionnaire included four items concerning the PMI’s stressful life events, such as financial problems, accidents or serious somatic illnesses.

Perceived stress scale

The 14-item Perceived Stress Scale (PSS) was used in papers II and IV. The PSS scale covers 14 questions about moods and unexpected situations in daily life such as, “How often in the previous month have you felt nervous and stressed?” measuring on a 5-point scale, “0=never” to “4=very often.” PSS scores are obtained by reversing responses (e.g., 0=4, 1=3, 2=2, 3=1 and 4=0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. The PSS measures the degree to which situations are rated as stressful, with high scores indicating high perceived stress. The items are constructed to show how unpredictable, uncontrollable, and overloaded participants find their lives. The scale also includes a number of direct queries about perceived stress. Chronbach’s alpha for the PSS is 0.82 (Cohen et al., 1983). It is commonly used in research involving young persons, and it was on that basis that we chose to use it in the study.

Support

The support-related items included questions about support received, need of support, and use of support. At first, four questions asked which types of support might improve their situation, such as web-based support, counselling, group counselling, or informational support, measured on a 4-point scale (“1=very much” to “4=not at all”). This question was followed by four questions to measure how frequently they used the various types of support, “Have you ever used any of the following types of support?”, measuring on a 4-point scale (“1=yes, often” to “4=no, never used it”). Three further questions asked about knowing where to turn for support or comfort (“1=yes, know for sure” to “4=no idea”). One multiple-answer item asked about their sources of support for the past four months, listing such resources as health care services, professional support, family, friend, school personnel, support groups, support associations, active- or passive web-based support, and books/magazines. All choices could be answered yes or no (III).

Caring situation

The Carers of Older People in Europe Index (COPE Index) was used in papers II and IV to gain a broad view of the experience of being a YIC and the actual situation. The COPE Index has 15 items to understand the caregiver’s role and perceptions about (1) the negative impact of caregiving (7 questions about the difficulties of caring for a person with illness, e.g., “Do you feel trapped in your role as a carer?”); (2) the positive value of being a carer (4 questions about coping with caring and finding caring worthwhile, e.g., “Do you feel that someone appreciates the support you provide?”), and (3) the quality of support for carers (4 questions about the different types of support provided from the family and health care services, e.g., “Do you receive good support from the health care services?”). All items measured on a 4 point scale, “1=never” to “4=always.” Each section of the scale is summarized separately to gain knowledge on each part of the scale. A high score in negative impact may indicate that the carer is less stressed in his/her role as a carer and a low score in positive value may indicate that the carer is less satisfied in the carer role. The total scores in quality of support shows whether the carer feels supported or not in the role of an informal carer.

Chronbach's alpha is 0.83 for negative impact, 0.66 for positive value, and 0.64 for quality of support (Balducci et al., 2008). Since no other scale measures the multiple angles of being an informal carer as well as the COPE-index does, this measurement scale was considered optimal for use in our research.

General perceived self-efficacy scale

The 10-item General Perceived Self-Efficacy Scale was used (GSE) in papers II and IV (Bandura 1997; Schwarzer et al., 2005). The instrument measures individuals' own belief in their ability to succeed in specific situations and to handle difficult tasks. The scale covers questions about goal-setting, effort investment, successful coping, facing barriers, and recovering from difficult set-backs, such as: I always manage to solve difficult problems if I just make an effort to do it. The items were measured on a 4-point scale, "1=not applicable" to "4=always". The total scores range from 10 (low self-efficacy) to 40 (high self-efficacy). In this study (II and IV) we used the Swedish translation of the GSE scale, with Chronbach's alpha 0.87 (Löve et al., 2012). The GSE scale has been used in many studies also with young persons. A recent study demonstrated that a single-item measure of self-efficacy showed better predictive validity than a well-established self-efficacy multiple-item scale (Hoepfner et al., 2011).

The well-being scale

The Well-being scale (WHO-QoL-5) used in paper II and IV asks five questions about how the person felt during the previous two weeks, whether they felt happy, fresh, active, and vital, e.g., "In the previous two weeks, how often have you felt cheerful and in good spirits?" The items are measured on a 5-point scale (1–5) that ranges from "1=very good" to "5=very poor". All scores are summarized and the total is multiplied with 4. The score range from 0 to 100. A higher score may indicate higher well-being. Chronbach's alpha is 0.87 (WHO 1998). The well-being scale is well recognized in youth research and is well used in the context of exploring young person's well-being.

Sociodemographic characteristics of the PMI

Five items asked about the PMI's sociodemographic characteristics such as sex, age, born in Sweden (yes/no), live alone (yes/no). One overall question about their relationship to the YIC was included: parent, sibling, relative or friend. To learn about the PMI's condition we asked why the PMI needed support, with multiple answers listed and allowed, including depression, bipolar disorder, anxiety, self-harm, ADHD/Asperger Syndrome, and eating disorder. One multiple-answer item asked about support received from professional health-care, with the following examples to choose from: psychiatric care, health care day center, special housing, no help, or other. (II and III)

Intervention

The intervention in this thesis comprised two different support interventions, a web-based support and a folder support. The interventions went on for 8 months, from June 2009 to April 2010. Both interventions were developed within the research group PsYoungSupport. The research group consisted of two PhD senior researchers (one

nurse specialized in psychiatric care and one occupational therapist), two PhD students (one specialized nurse in psychiatric care and one psychologist), and one communicator (a journalist). The four health-care professionals in the research-group also constituted the “support team” at the web-site. The text material published on the web and used in the folder was all developed by the research team and revised by the communicator to common and accessible language for young persons, and the communicator also frequently produced and updated new material on the web-site and the blog. The technical development of the web-site was done by two system engineers and one PhD candidate, who all were associated with the project group.

Web-based support

The development of the web-based intervention, reported elsewhere (Elf, et al. 2012), took place in phase II, with the focus and intention to produce support and information adapted to the YIC’s needs, which were explored in phase I (Elf et al, 2011) (Figure 1). The European Commission has agreed on a number of quality criteria for health-related web-sites (eEurope, 2002), which we followed when designing the web-site. The commissions’ criteria are transparency, statement of sources for all information provided, protection of privacy and personal data, updated information, accountability, and accessibility. The web-site clearly stated that it was provided by Vårdal Institutet (The Swedish Institute for Health Science), and University of Gothenburg, Sweden. It was also stated that the web-site was developed in cooperation with relatives and close friends of persons with mental illness. The web site (www.molnhopp.nu) contained asynchronous information about how to manage the situation of being a YIC of PMI; what to do for your relative or close friend who suffers from mental illness; how to take care of yourself as a YIC; links to other quality secured relevant web-sites and networks; and information about mental illness, such as early signs and symptoms of mental illness (Figure 3). The web-site also contained interviews with young persons and celebrities in Sweden who had released a biography or engaged in interviews about their lives and their experiences of being a YIC. There were also book reviews related to the subject. The YICs’ could choose how active they wanted to be on the web-site by visiting the site to read the reports, or to be visibly active by posting a question to the support team (two senior researchers and two doctoral students), who would answer the questions professionally and supportively. The questions and the answers were then posted on the web-site. Participants could also voluntarily write on the bulletin board and start a discussion with the other visitors. All discussion threads were visible on the web-site for all participants to join. We made it clear to the participants that this was intended to be a stand-alone intervention, and that we would be as transparent as possible in the process.

Folder support

The folder support consisted of a folder which was a triple-folded A4-size paper that contained information on available support such as Children’s Rights in Society (BRIS), the Red Cross, and other volunteer organisations available to young carers in the Swedish society (Figure 4). Contact information such as phone numbers and email addresses for each organization were all listed in the folder. The YICs could contact

any of the organisations if they needed to. The folder was white and with a life buoy image on the front page. The folder was designed by the communicator in the project PsYoungSupport.

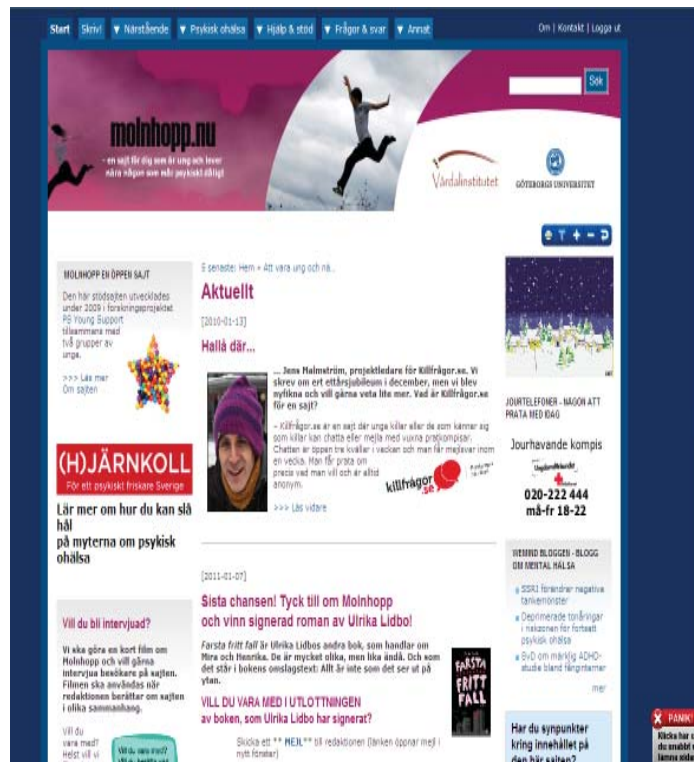


Figure 3. Screen print of the web-site used in the intervention.



Figure 4. Screen print of the folder used in the intervention.

Data analysis

Qualitative analysis

In paper I, qualitative content analysis was chosen as the method for analyzing the transcribed interview texts in order to gain a deeper understanding. Content analysis is a research method used to make visual well-based conclusions from e.g. a text in a specific context (Krippendorff 2004). This analytical method was developed to uncover underlying meanings and to predict events in texts (Krippendorff 2004). The researcher can then draw applicable and valid conclusions from the data into context (Baxter 1994). Content analysis elicits new insights and increases understanding of a phenomenon or a practical action (Baxter 1994; Krippendorff 2004). To find prominent patterns and themes, content analysis is performed step by step (Patton 2002, pp. 452-471). The first step is to divide the text into meaning units that relate to the research question(s). As a second step the meaning units are condensed and labelled with codes that describe the content of each meaning unit. In the third step the codes are sorted into subthemes. This makes it possible to abstract the subthemes to main themes, which is the fourth step in the analytic process (Krippendorff 2004). To ensure trustworthiness, citations from the interviews are used in the presenting text. The analysis brings new insights to light and increases the understanding of phenomenon in question (Krippendorff 2004).

In study III a mixed method design (Creswell 2007, Carr 2009) using the qualitative data from the interviews (phase I) and the written text in the collected surveys from the intervention (phase III) was used to analyse the data according to qualitative content analysis. Mixed method design allowed us to gain overall strength in the findings, was well suited to the data collected from the two different strands, and provided the opportunity to gain a deeper understanding of experiences and meanings (Baxter 1994, Creswell 2009). All the qualitative data (from phase I and III) in study III was analysed with NVIVO9 (QSR International, Pty, Ltd, 1999-2010), a software program for qualitative research. In the first step the interview text that was relevant to the aim of the study was uploaded into the program. The meaning units were identified and coded throughout the whole document in the second step. In the final step all codes were sorted into subthemes, depending upon their meaning. All codes that provided similar information were grouped together, allowing us to understand the pattern of the underlying meanings in the texts.

Statistical analysis

Data were analyzed using IBM SPSS statistics version 19 (SPSS Inc., New York, US). For all tests a p-value of .05 was regarded as statistically significant (Polit, 2012). In papers II and IV descriptive and comparative analyses were chosen to explore and analyse the data. Descriptive data, means and standard deviations, were used to present quantitative variables, and frequencies and percentages were used for categorical variables, in order to present sociodemographic characteristics, e.g., for sex, age, level of education, and occupation in study II, III, and IV. To compare the differences between the groups in these studies (II, III, and IV), the Chi-square was used (with percentages) on all demographic data in each study for continuous variables. For continuous variables, mean, standard deviation (SD), median, and min-max were calculated,

and for categorical variables, number (n) and percentage (%) were calculated. For the ordinal scale variables, the COPE-index, self-rated general health, self-efficacy, PSS, and the well-being scale, the Mann-Whitney U-test was used. To compare the interventions in paper IV the Fisher exact test was used for dichotomous variables and the Mantel-Haenszel Chi square exact test was used for ordered categorical variables. In paper IV the data was analysed both with intention to treat (ITT) as a primary analysis and also as a per protocol (PP) analysis, in order to capture the broader impact of the interventions (Eysenbach et al., 2002). All variables in paper IV were analysed at baseline (T1), 4 months (T2), and 8 months (T3), and as a change from baseline to 4 and 8 months, as the primary change was from baseline to 8 months.

Power analysis

To achieve 80% power ($p < 5\%$) in the primary outcome variable, and to discern a 9% change in the web group in perceived stress outcome compared to an expected change of 0.5% in the folder group, 95 persons were needed in each group due to expected drop-outs during the 8 months follow-up; one fundamental issue in eHealth is that a proportion of people will not use the intervention or will use it only rarely (Eysenbach et al., 2002). Also, annual national surveys (Swedish National Board of Welfare, 2011) show that this target group of young persons are likely low responders, since they are at an age when an active lifestyle filled with daily tasks and obligations such as study, work, or moving could lead to discontinued use of structured interventions (Arnett 2002).

Trustworthiness, validity and reliability

Important factors to establish trustworthiness in the qualitative analysis (I and III) were taken into consideration by addressing and obtaining credibility, transferability, dependability, and conformability (Guba 1981). Credibility in qualitative research refers to confidence in the truth of the data. According to Guba one way credibility can be established is through data-, investigator-, theory- and method-triangulation, which refers to using multiple data sources, multiple individuals to collect and analyse the data, multiple perspectives to interpret the data, and multiple methods to address the research question (Guba 1981, p. 362). Transferability refers to the generalizability of the data and the extent to which the findings can be transferred to other groups. Transferability can be established if researchers are able to provide sufficient description of the data in their reports to allow others to evaluate the applicability of the data to other contexts (Guba, 1980). Dependability refers to the stability of the data over time and conditions, which can be established by using an external reviewer of the data. Confirmability in qualitative research can be established by two researchers independently agreeing on the meaning and relevance of the (Guba 1980, Polit et al., 2012).

To maintain the strong quality of the studies (II, III, and IV) and to establish validity and reliability in the quantitative analysis different steps were carried out. Validity in quantitative research relates to the degree to which an instrument measures what it is supposed to measure (Polit et al., 2012). The reliability of an instrument refers to the measures' or scales' consistency in measuring the construct, its accuracy, and its stability (Polit et al., 2012). The internal consistency of the measurement scales

can be measured by Chronbach's alpha, which should have a minimum target value of 0.70 to be acceptable (Polit et al., 2012). In interpreting quantitative results, the risk of Type I and II error should be taken into consideration. The risk of type I error, in which the null hypothesis is rejected, can be reduced by setting the level of significance usually at 5%. To also avoid type II error, in which the null hypothesis is accepted even when it is false, the sample size should not be too small and should be determined in advance (Polit et al., 2012).

Ethics

All papers in this thesis followed the World Medical Association's Helsinki Declaration 2000 (WMA, 2000). Approval for the studies was obtained from the Regional Ethical Review Board in Gothenburg (Dnr/762-08). The young persons who were asked to participate and agreed to be included in the first phase of the study were provided with written and oral information; they were informed that their participation was voluntary and confidential, and that they had the right to discontinue their participation in the study without giving a reason. Parents or legal guardians of participants younger than 18 years were informed about the study and needed to give their written consent for their children to participate. All participants who were recruited thru a recruiting company were informed verbally at the first contact that they had the right to leave the study without giving any reason and at any time they wished; this was also clearly stated in the welcome letter that all participants received.

In the intervention (IV) each new participant in the web-based support group received a unique user name and password, which was registered by the researchers as the participant entered the study. All usernames were created by the research team to avoid any offensive usernames. The e-mail address that was included in the database was encrypted and could only be de-encrypted by the responsible researcher. The decoding key was kept in a safe-deposit box. Only the researchers could use the registered data as data-base files (e.g. SPSS) for further editing and evaluation. The web-site was locked and only those who had usernames could access the web-site, but it was clearly stated that as soon as the intervention was over the web-site would be available to the public and anything published would be accessible, though unidentified, to anyone who visited the site. The research team took precautions and visited the web-site regularly to remove any offensive comments and to answer questions from participants. Any participant who would have posted alarming comments or shared any self-destructive comments in the questionnaire would have been contacted by a senior researcher specialized in psychiatry and directed to an appropriate support or health care service.

FINDINGS

The main findings of the four studies are summarized and presented below, first the young informal carers' needs for support and social interaction in the informal carer role, and then their experiences and use of support. The findings are presented under the main headings "young informal carers need of support and social interaction" and "young informal carers use of support."

Young informal carers need of support and social interaction

Responsibility as an informal carer

Having responsibility as a YIC of a PMI meant in several cases being engaged in the role and providing care and support to the PMI regardless of one's own circumstances (I). The YIC provided whatever support they could to their loved ones unconditionally. The YIC were stressed because they took on involuntary responsibilities in their situation as an informal carer (IV). These included daily worries about the PMI and making sure that they were well. YIC felt they had no choice but to take on the responsibility for the PMI since no one else did or was capable of doing it (I). Because they were considered to be one of the PMI's closest person, it did not matter if they supported and cared for a family member or a friend (IV). The YICs needed to reduce their stress, which would benefit their health in the long run (IV). If the YICs could reduce their stress they would be more at ease in their informal carer role, which would also benefit the PMI (I). The YICs appreciated having contact with someone such as a parent or a friend who knew how to react in different kinds of situations. The YICs needed someone who could tell them what to do in these cases, but even just having someone to talk to and use as a sounding board might have helped (III). There was a difference in how friends who were YICs felt satisfied with the support that they were offered from their social network and professionals, and how family members of PMIs felt (II). The YIC who were family members were not satisfied with the quality of support they received from their own family or friends or from health and social services (II). They needed more attention and awareness from persons in their social network of what they were going through. YIC who supported friends were more satisfied with the quality of support they received from their own family and friends than family carers were.

Experiences of health care services

Because the YIC were close to the PMI, they felt it was in their responsibility to accompany them to the health care services when they were acutely ill and when it was beyond their level of expertise to handle the PMIs' condition (I). The YICs needed to be involved in the care of the PMI whenever the PMI had to be in contact with psychiatric care, to cooperate with the professionals, and to share with them what they knew about the PMIs' condition. This was important to them because they felt that they were a part of the PMIs' situation because they shared their daily lives with the PMI and knew important details about the PMIs' condition in their illness, their history, and what had been happening recently. The YIC needed to tell their part of the story to make sure that the professionals had all details when planning the care for the

PMI. However the YICs felt ignored by the psychiatric health services (III) and this broke their trust in the psychiatric health care system. YIC were not confident enough to believe that they were welcome to seek help when they were in need of it, meanwhile they were taking on the responsibility of care and support of the PMI when the psychiatric health care services failed to do so (III). YICs were in need of support even when the PMI were no longer under on-going treatment in the health care services. The YIC described their fears that as soon as the support services ended for the PMI, they would also end for the YIC, even if they still needed them. They tried to search for support, such as information on the web, but failed to find anything appealing to them (III). YIC needed the support to be suitable and to be addressed to them as a target group; even if they did find some information on the web, however, they did not find it trustworthy or serious enough (III).

Value of their relationship

Having people in their lives who showed sincere concern made a difference in lightening the burden of being an informal carer (I). The YIC felt that they were surrounded by people who could not understand that their relationship to the PMI was in fact meaningful to them. Those who were family members of PMI experienced higher positive value in their informal caring role, such as coping with caring for a PMI, finding caring worthwhile, and feeling appreciated by the PMI for their care, than did YIC of friends (II). They also experienced difficulties in maintaining their relationship with the PMI without being in the supporting role, since they are the ones the PMI blame when they did not have insight into the severity of their condition (I). The YICs felt that once they assumed the informal carer role it changed their previous relationship to the PMI and they became a kind of guardian who always watched the PMI and interfered with how they acted or what they needed to do (I). Both groups of YICs, family members and friends, indicated that it was important to know one's own limits and to accept support when it was offered, but they did not reflect upon that during an acute situation with the PMI. Instead the YICs tried to manage the situations on their own without any professional support (III).

Commitment and emotions

Taking responsibility for a PMI meant dealing with severe situations as the PMI's symptoms increased and became acute (I). YIC needed someone to talk to who was experienced and could be available to them with advice in times of crisis. They needed someone who could encourage them in their situation and give them concrete advice on strategies for handling their informal caring role (III). There was no difference between the family group and the friend group in where they would turn if they needed support (I); they usually turned to their parents, siblings, or friends. More seriously, the YIC experienced daily exposure to the PMI's suicidal thoughts, suicide attempts, and unwillingness to take care of themselves (I).

The YIC felt trapped in their daily life, which evoked emotions of sadness, anger, frustration, and loneliness (I). The YIC worried about the PMI, and most of the time they could not ignore those feelings. They dealt with it on their own, by trying to find positive things in their situation to think about (I). Still the emotions they experienced on a daily basis were mostly the negative feelings mentioned above that first arose

when they discovered mental illness in a person who mattered to them, who used to be well functioning in their lives, and who has suddenly changed in mood and personality. The YIC felt sorrow about the PMI's changed personality; however, they mostly chose to ignore these feelings to focus on the PMI's well-being (I). YIC were able to care regardless of the circumstances because they truly wanted to engage in the PMI's care (III). This dedication and denial of their own feelings had consequences for the YIC; YIC who were family members of PMIs were significantly more irritated in daily life than YIC of friends were, while YIC of friends were more negatively affected by the impact of their caring situation, such as feeling trapped and having difficulties with their relationship with the PMI and with their emotions (II). Friends were also more prone to using non-prescription drugs and had more legal and financial problems to deal with than family members as did, which could also increase their levels of stress (II).

Young informal carers' use of support

Strategies for enduring

Young persons who supported persons with mental illness lived in the shadow of that person's need for support, when they themselves were in need of support (IV). Still, most YIC did have someone to turn to in case of emergency, such as a parent, a sibling, or a friend (III). They used individual management strategies to nourish their own well-being and to maintain control of their intensive daily lives with the PMI (I). When the situation elevated beyond their capacity the YICs withdrew and mainly focused on what made them feel stronger, such as remembering the positive aspects of their situation. This positive thinking gave them energy to protect themselves, to stay strong enough to stay longer in the situation, and to bear their situation (I). Those who did not withdraw when the situation was unbearable used self-destructive behaviour instead to attract attention from professionals or school personnel to themselves and to the PMI. YIC treated people in their social network carefully in that they shared with them only selected details, in order not to exhaust their friends and risk losing the persons who cared for them (III). They revealed only some details to one person in their social network and saved other details for another person in whom they felt confident. They did not commonly take advantage of the support services available to them in society, such as school personnel, professionals, support groups, or youth centres in society (III). They felt strange in school because of their burden as an informal carer, but they wanted to be noticed rather than to take the first step and tell someone about their situation. Family members who cared and supported a parent would search for other adult role models when their parents were incapable of fulfilling their role in the YICs' (I). These YICs usually turned to adults in school or to other family members in their surroundings in whom they had confidence. Family YIC needed to have an adult in their life who knew enough details about their situation, an adult who would stay with them along the way to give them the guidance in their own daily life choices, such as maintaining their school attendance and managing their studies (I).

Value of support

YIC had only some or little knowledge of where they could turn to for support when they were in need of it (III). Although most of the YICs who reported that different

types of support, such as web support, group counselling, counselling, and information would probably improve their situation as informal carers, few had actually used any of it (III). The findings from the RCT intervention confirmed low adherence to web-based support and folder interventions (IV). However, each of the interventions (web-based support and folder support) was shown to be of value; the use of folder support decreased the stress level in the folder group and the use of either support increased well-being in both groups (IV). The caring situation was also improved for both the web- and the folder group (IV). Findings showed that YIC were used to turning to the web when they wanted to search for information about mental illness and learn how to take care of a PMI (I). In their opinion the web was a place where they could stay anonymous and share their stories, thoughts, and feelings (III). However, even though they easily accessed the web when they needed, they still used their social network, in particular parents, siblings, and friends (III).

Reflect over line of actions

When the PMI were feeling mentally better, the situation for the YIC was also eased, and there was an opportunity to see what had happened with the PMI and how they could have managed a difficult situation differently (III). They regretted that they did not try to find professional support and help when they needed it, instead of trying to handle difficult situations on their own without really knowing what to do (III). YIC who were family members had more experience in their informal caring role because they had cared for the PMI for a longer period of time, and they reported less satisfaction with the quality of support offered to them by the health care services and their social network than friends in an informal carer role did (II). Because of that dissatisfaction and the lack of appropriate support, the YIC turned to people who were close to them, and several times to the PMI, instead of to professionals and the psychiatric health care services. They did this because the PMI knew most of the details of the situation, were always available, were the closest to the YIC, and knew better than anyone what the YIC had to go through. This saved the YIC the effort of involving others, who to their knowledge would not have understood and had no experience of what to do or how to handle situations with the PMI. (III)

DISCUSSION

General discussion of the findings

Young persons who are informal carers of persons with mental illness, and are themselves in a developing period of emerging adulthood, have in this thesis been found to shoulder a responsibility that is sometimes beyond their capacity. It was shown that the role YIC assume because of the responsibilities of caring can impact on their lives in several ways. In the following section the young informal carers' daily life experiences and the meaning of receiving support to maintain this role will be discussed.

Young informal carers' everyday life experiences

The findings in this thesis reveal that YIC experience involuntary responsibility, regardless of the circumstances, to care and support the PMI and they know that it is their decision making that will force the PMI to make the effort to recover. The YIC take on responsibilities, such as accompanying the PMI to health care services - sometimes against the PMI's will - because they do not think that anyone else will take it on and they do it to help the PMI. According to Levinas (1985) the experience of encountering the face of another is what brings us absolute responsibility. The scope of responsibility is established in a person by considering the expectations and possibilities created by a shared inheritance. It is the face of the other that calls the person to responsibility towards another human being, to protect and care for that person. To look into another person's face, e.g. in this case that of a PMI, and to become aware of the frailty and need of the other, is what perhaps breaks through to a young person who becomes a YIC (Levinas 1985). Being a YIC puts young persons in the role of handling a responsibility more appropriate to an adult, as reflected in other studies (Van Wijgaarden et al., 2004, Aldridge 2006, Becker 2007; Grant et al., 2008, Hedman Ahlström et al., 2011).

However, YIC do not hesitate to take on the informal carer role and handle daily concerns about the PMI on their own, although they are themselves in a phase in life when they would be better off in a stable and encouraging environment (Arnett 2000). YIC who take responsibility for a PMI must therefore be considered a vulnerable group according to Arnett (2010) because they handle difficult situations with serious responsibilities daily, alongside all of the normal stressors of life, while they are in a sensitive developmental phase. All the possibilities that are promised the young, and the decisions they have to make may also contribute to the stress that the YIC perceive in daily life. Today's generation of emerging adults is a generous generation that holds great promises to improve the world with their action (Arnett 2013).

YICs in this study showed high self-belief in their own ability to handle difficult demands in life, which indicates that these YICs have high general self-efficacy. However Twenge (2013), who studied students' development from adolescence to adulthood, claims that there is a cultural change in today's industrial society, which shows a generational increase in narcissism among high school age people to adulthood. Arnett does not agree with this; instead he points out the danger of confusing high self-belief

with narcissism, since it is common that young persons in this phase of development have high expectations for life and high hopes that those expectations will bear fruit in the future (Arnett et al., 2013). This agrees with the findings in our studies that YIC have high self-belief in their abilities to handle unexpected situations and that they feel confident in their role as YICs.

YIC feel alone in their situation and they miss having a responsible and understanding person to talk with and turn to in difficult times. According to both Twenge (2013) and Arnett et al., (2013), young persons are in a stage in life when anxiety and depression are high, as is also shown in annual national Swedish reports (Swedish National Board of Welfare, 2011). In this study more than half of the participants reported feeling lonely. This was also echoed in a large national survey (Arnett et al., 2013) conducted in USA, in which more than half of the 18- to 29-year-olds who participated agreed with the statement “I often feel anxious” and “I often feel depressed.” It is not surprising that young persons in this stage of life feel anxious since they are making their way towards building the foundation of an adult life, which involves trying out possibilities that do not always work out as expected. YIC try to strive for their goals in life at the same time as they provide care and support to a PMI. They try to focus on the positive aspects of their informal carer role to be able to gain strength from their positive thoughts. Björklund (2007) also wrote that high expectations and optimism are valuable psychological resources for emerging adults during what is often a stressful and difficult developmental phase.

YIC in this study turn to parents, siblings or friends rather than to professional support such as counselling, school health care services, or youth centres. Although they do think that professional support would improve their situation, they still prefer to go to their social network for support. Social networks are important to individuals since they fulfil the person’s needs through the interpersonal exchanges (House 1981; Bowling 1991, Skärsäter et al., 2003, 2003; Hedman Ahlström, 2011). YIC provide emotional support to the PMI if they need it, and if the PMI need professional support the YIC try to encourage the PMI to seek health care services. YIC expressed their need to be involved in the care of the PMI and the importance of not being left out of the PMI’s care. This was found in other studies, in which relatives of persons with mental illness experienced a lack of involvement in the PMI’s care and dissatisfaction with the professionals’ approach towards them whether they felt involved or not (Syrén et al., 2010; Ewertzon et al., 2011). Negative encounters with psychiatric health care professionals are the main reason for lack of trust in the services (Sternswärd et al., 2008; Dahlqvist Jönsson et al., 2010). It was important to YIC to feel noticed by health care professionals. YIC consider themselves the PMI’s significant others since they share their everyday life experiences together. Giddens (1991) argued that social interactions with other people that contribute to the reflexive project of the self can in fact imply that these people become significant others to the individual whether they are family or not (Wright et al., 1996; Benzein et al, 2008). Also Mayerhoff (1971) also stated that the “appropriate” other for an individual is someone who enables a person to be complete, which creates a better position for growth and towards recovery.

The findings showed that the YIC felt people in their surroundings did not understand the meaning of their relationship with the PMI, which made them want to withdraw. Other research shows that those who are close to a PMI do withdraw from their own activities and concerns in their own lives to stay close to the person suffering from mental illness (Hedman Ahlström, 2007). This finding is alarming since it may put the YIC in an isolated environment in which they miss the positive stimulation important for their own development in this sensitive phase of emerging adulthood (Arnett, 2002). They should be a part of society at that age instead of outside of it. According to Levinson (1978) “an individual’s life structure is shaped by his or her social and physical environments, which include family, social network, work and to some degree also by religion, race and economic status”.

Meleis (2010) argued that young persons in the developmental transition to adulthood are in fact affected by their environment, family, and close friends. If any dramatic change affects their friends or family, they too will become affected in their developing phase of transition. Being in an informal carer role to a PMI does seem to have effect on one’s own well-being and health (Moore et al., 2006, Hedman Ahlström 2008, Grant et al., 2008, Swedish National Board of Welfare, 2011). That also became evident in our study as the YIC were shown to be affected by their informal carer role and stated that they too needed support to be able to manage their situation.

Commitment plays a central role in the connection between the individual and society. In maintaining a good relationship with someone who is cared for, commitment is considered an important variable because it is a key motivational factor that has a powerful influence on a relationship (Becker 1969). To witness daily a person who has been and is emotionally important change from being a well-functioning parent, sibling, or friend to a person who does not care for themselves raises emotional concern for the other. This change in the personality of the PMI, and the related change in the self from child, sibling, or a friend to some kind of supervisor or guard affect the YIC negatively with sadness, frustration, and anger.

According to Hirschi (1969), who emphasized that family, friends, and others in our social network affect our lives in several ways, the individual is a direct descendent of the actions of those in the close social circle. During the critical time of young adulthood in which individuals need strong positive social ties to be able to represent society in the best way, negative ties will most likely provide negative results. Arnett (2000, 2002, 2006) has stated that young person’s rely on their social networks to find the strength and the positive energy to manage the difficulties in the development of their emerging adulthood. This is in line with the results from our study in which the YIC state that their main source of support comes from their social network.

The importance of support to maintain the informal carer role

Findings in this thesis reveal that YIC live in the shadow of the PMI’s need for support, when they also need support themselves in their informal carer role. The YIC use their own management strategies to endure their situation and nourish their own well-being in order to stay in control in difficult times. When the YIC feel that the

situation is affecting them in a negatively and the burden is too great they handle the situation by withdrawing and focusing on tasks and activities that bring them positive energy. A serious finding in this thesis is the self-destructive behaviour used by YIC in an urgent need to draw attention to themselves. According to Morse (1997) enduring is connected to suffering, because it is in the enduring state in which emotions are repressed and in the suffering state that they are released. Morse (2001) has described enduring as “suppression of emotions”. Blocking emotions allows the individual to handle the situation, but it does not give any relief to the individual. By enduring, people focus all their energy on “holding on”. To escape suffering people are more likely to focus on distracting behaviours such as intense physical exercise, other hobbies, or even out-of-control laughing. This may be one reason why the YIC in our study expressed self-destructive behaviour when they felt breached by the society and their social network.

YICs in this study had fair knowledge about where to go for support, and were well acquainted with the types of support society has to offer them. Yet on analysis, the YICs experiences of support shows clearly that their choice has been to turn to their social network for advice and support and to the internet for information because the available support does not address them as a target group nor is it serious enough. This finding is in line with Gould (2002) who studied the help seeking behaviour of young persons and found that the majority in his study demonstrated a preference for informal, nonprofessional help over formal, professional help. He also found that nearly one fifth of the participants used the web to obtain help for emotional problems.

According Findahl (2012) a majority of all internet users search for health-related information on the web, and Santor (2007) found that young persons with help and emotional problems most frequently used the web for support. The frequency of using the web as a carer was studied by Fox (2012) who found that carers are significantly more likely than other internet users to state that their last search on health-related information was on behalf of someone else that they know. In recent years mHealth has also been evolving, most likely because of the increased use of mobile phones. In Sweden almost all (97%) Swedes aged of 16 to 75 have a mobile phone (Youth & Media 2010). In 2011 the most frequent users of mobile internet, particular social media, were 15 to 24 years olds (Findahl, 2012). The use of eHealth and mHealth may have an effect both physically and psychosocially on health (Gustafsson et al, 2003, Thomée et al, 2010). Although computers and mobile phones could be considered to be different they still share psychosocial aspects in common, such as easy access to the web and contact with one’s own social network (Sjöberg et al, 2001, Gustafsson et al, 2003, Thomée et al, 2010).

This study on the other hand confirmed low adherence to using the web- and folder-support interventions, yet both groups decreased their stress level. This is essential since stress has considerable consequences on the YIC emotional well-being (Moore, 2007). This finding might confirm that both interventions could be effective in reducing stress depending upon the user’s preferences and the development of suitable and appropriate support adapted for person’s needs (McCormack et al., 2010, Ekman et al., 2012).

An important finding in this thesis was that YIC often used the PMI for support instead of involving others. They did this because they did not think that they would get any understanding from people from the outside the on-going situation with the PMI. Instead of turning to professionals or some other source of support, they preferred to go to the PMI for support and debriefing. This finding is valuable since it has been recognized that PMI feel a shamed to burden young persons who are close to them (Johansson et al., 2012).

In that study it was found that the PMI did not want the YIC to visit them when they were admitted to the hospital because they felt it would be stressful for the YIC to see the PMI in an acute phase of their illness (Johansson et al., 2012). These two aspects suggest that the YIC plays an active role in the relationship with the PMI while the PMI stays passive and tries to spare the YIC stress and burden. In this thesis the findings showed the opposite, and we found that the PMIs relied on the YIC when they were ill.

Methodological considerations

To learn about how young informal carers of persons with mental illness handle their everyday lives and at the same time to evaluate web-based efforts provided for these YIC required a multi-method research approach. This thesis comprises four papers involving a variety of design and methods. A qualitative approaches was used (I and III) to learn about the daily life experiences of YIC through an interview guide (I) and open questions on a semi-structured questionnaire (III), and a quantitative approach was used (II–IV) to gather data through self-administrated questionnaires to evaluate two interventions provided for YICs. The qualitative approaches emphasises the understanding of people's lived experiences and gives researchers room for their own interpretations of the analysed data, which may be considered to be subjective. Interpretation is expected and appropriate as long as the researcher can distinguish between description and interpretation (Schlechty et al, 1982). The open questions in the questionnaire did not provide us with as much depth as the data elicited through the guided interview. In quantitative research the limits are in gaining knowledge about complex human experiences and the results have a tendency towards generalization (Polit, et al., 2012). The strengths and limitations in each paper will be discussed in this following section.

For the qualitative studies (I and III) participants were recruited by the research team, which put in a great effort to personally hand out thousands of leaflets in areas where young persons would be expected to gather in the west region of Sweden; however, only one participant was recruited through such effort. The advertisements in the newspapers gave the best results as the other participants were recruited. The complexity of recruiting participants may be explained by this target group' active and sensitive phase of life as they live a mobile life and might have not settled down yet (Arnett 2002). Another option for recruiting participants might have been to recruit through psychiatric departments. However, for several reasons, we decided early in the process, before the start of the intervention that that was not an option: the target group was not patients, but healthy young persons in the general population; we would have had to follow the departments' strict health-care web-policies on how the

interventions should be constructed and how the project should be guided, but this study was planned from the beginning to follow a participatory design, in which the young persons and their needs as informal carers would influence the intervention; and we wanted to reach out to a broad cross-section of all young informal carers, not just those who were known to the psychiatric departments.

The participants were recruited for the interventions by a recruitment company, which has both positive and negative aspects. A recruitment company may have the capacity we lack to reach the large number of total participants needed to power a study of this design, since in the last decade it has become more difficult and challenging to recruit young persons for health-related research (Fanner et al., 2012). The negative aspect is that the research team had little control over the process of recruitment. The company used structured communication based on our guideline of what to ask the young persons they telephoned and how to present the research study. However, it might have decreased the dropout rate at baseline if first contact and source of information for the participants had been the research team and not the recruitment company. A limitation in studies II, III, and IV therefore is that the reason participants dropping out of the study is unknown. However, since the target group was the general population, there was no opportunity to discover why participants decided to drop out. This was opposite the qualitative papers (I and III) which had no dropouts and only one person excluded for not fulfilling the inclusion criterion of supporting a person with mental illness. The participants were also awarded with two cinema tickets for their participation.

In the quantitative studies (II-IV) the drop-out rate was within expectations for long-term follow-up studies and was taken into account according to the performed power analysis. Also, this target group of YIC face several changes, such as graduating from school and moving to other cities to study in college or university (Arnett 2002); as has been recognized in other studies with young persons, it was difficult to obtain a high response rate as this target group has a mobile way of living (Garrett et al., 2000, Faden et al., 2004, Morton et al., 2006, Fenner et al., 2012). To keep the participants in the study two reminders were sent out, each participant received a lottery ticket (value about 1 euro) after they had answered each questionnaire, and those who completed the survey received two cinema tickets.

To develop an intervention with an end-user perspective to increase its usage, the interventions were constructed using a PD (Spinuzzi, 2005). The text was reworked with the communicators to address young persons. This was an assumption in the project in order to make it easier for the YIC to absorb the information provided for them on the web-site or in the folder. The web-site was also frequently updated and managed by the research team as each person in the research team was responsible for running the web-site one week at a time.

The researchers monitored the activity on the web-site in case any offensive posts were posted. Precautions were taken in accordance with the European Commission quality criteria for health-related web sites (Commission of the European Communities, 2002). The development of the web-based intervention (IV) was reported in another thesis (Elf et al., 2013).

To improve the reporting of the RCT study the CONSORT statements were used (IV) (Boutron et al, 2008). Additionally, as the RCTs of web-based interventions pose specific issues and challenges, the eHealth specific CONSORT extension guideline and checklist were also used. We also followed The CONSORT EHEALTH extended items concerning adherence to the intervention, to report whether the participants used the intervention or not, how often and how long (Eysenbach, 2011). The CONSORT guidelines require researchers to report and address all important details in RCTs. The guidelines also functioned as a tool to make sure all important areas for reporting the trial was covered.

To evaluate the interventions (IV) a questionnaire consisting of 64 questions was sent out to all participants. Some of the embedded items were commonly used self-rated single-answer questions and some were well used measurement scales. The constructed questionnaire had been face validated by the research team; however, more validity testing was needed, which will be considered in future research. The measurement scales were carefully chosen and have considerably good internal consistency and reliability (Polit et al., 2012). The self-rated single questions provided knowledge about the sociodemographics, health, and social interactions of the participants along with some information about the PMI. The PSS, GSE, and Well-being scales have all been used previously in studies with young persons.

The COPE-index is more commonly used in studying caregivers of elderly people. One other study (Dahlqvist-Jönsson 2011), however, also used the COPE-index to study younger relatives of PMI. Because the COPE-index covers important aspects of the caring situation we found it important to use since we wanted to gain more knowledge about the YICs caring situation. The measurement scales were used in three of the papers (II, III, and IV) and compared different groups according to the aim of each paper, which provided rich quantitatively reliable data.

The internal and external validity of the data collection describe aspects of its quality and will be further discussed here to ascertain whether any conclusions can be drawn from the results (Polit, et al., 2012). The internal validity of the intervention was taken into consideration during the research process, by randomizing as homogenous groups as possible, in order to rule out other factors that might have been responsible for the effects measured. External validity describes the degree to which the results of the study can be generalized to other samples or settings (Polit et al., 2012). The results of the intervention paper (IV) can be generalized because of the satisfying sample size and the reliable follow-up over time. However, the follow-up from baseline to 8-months could be considered not enough to consider the participants to have become engaged in the interventions provided for them, since visiting a web-site to search for health-related information is not something a person would be expected to do daily basis, but rather when needed. To strengthen the reliability and to avoid type 1 and type 2 errors, the level of significance was set to .05 and sample sizes in the studies (II, III, and IV) were sufficient (Polit et al., 2012).

In the qualitative studies (I and III) the interviews were all conducted by two senior researchers and one PhD student. It was an advantage that the participants could de-

cide which interview format they preferred. The semi-structured interview guide, with not too many questions, and the comfortable environment allowed participants to feel comfortable sharing their experiences. The interview data was rich and contained satisfying data. The content was analysed according to Krippendorff (2004) and Baxter (1994) processed between all authors of the papers (I and III) which make the findings trustworthy. The quality of the original interview determines the quality of subsequent analysis in the way it is verified and reported (Kvale 2009). Credibility was established and strengthened by the use of multiple data sources and several researchers to interpret the data (Guba 1981). The accurate reporting of the analysis process enables transferability and applicability of the data into other contexts (Guba 1981). For the dependability and confirmability of the data, we included more than one external reviewer of the analysis and documented the analytical decisions made during data collection and analysis (Guba 1981). Numerous quotations from the participants were presented in the findings of each paper (I and III) for the reader to be able to estimate the quality of the findings.

All of the participants in this thesis signed a consent form which clearly stated that they could withdraw their participation at any time and without giving any reason. The chance of any participants becoming emotionally affected was discussed by the research team and should any alarming comment be made by a participant, a senior researcher would contact the participant and assist him or her to seek appropriate help or support for their condition. This was necessary only one time during the entire research process. These precautions were made to protect the participants because this is a sensitive part of their lives that they have chosen to share with the researchers during a sensitive time of their lives, and this had been taken into consideration during the entire research process (Polit et al., 2012).

CONCLUSIONS

Young persons who are close to a PMI and are themselves in the developmental period of emerging into adulthood were found in this thesis to take on an involuntary responsibility that was sometimes beyond their capacity to meet. The on-going pressure of low staffing levels and budget cuts in the psychiatric health care services have led to the transfer of responsibility for the care and support of a PMI to that person's social network. Young persons who are informal carers of a PMI feel that since no one else seems to care about the PMI or know anything about their mental illness, they must take on the informal carer role. Supporting a person in the family can have higher positive subjective value than supporting a friend, however friends experience higher quality of support that they receive from their social network and professionals than what YICs who support family members do. YIC provide unconditional support for the PMI and maintain a constant state of readiness for unexpected events to happen to the PMI because of their mental illness. As difficult as it is to witness the change in a person who is a family member or a friend and to recognize their suffering in the mental illness, YIC still find management strategies that allow them to endure their situation and handle responsibilities that should more appropriately be assigned to an adult or a professional such as professionals in a psychiatric health care department. YIC turn to their social networks for support and understanding about their situation as a YIC, but they often felt that they were not being taken seriously. They experienced that the persons in their social network had no understanding of how meaningful their relationship with the PMI was. YIC also felt that persons in their social network did not know what to say or what to do, which resulted in the YIC turning instead to the PMI for support or to use them as a sounding board.

The YIC lack support from professionals in psychiatric health care services, but want to be involved in the care of the PMI when they seek for professional psychiatric care. YIC who are friends of PMI feel that they are left out by the professionals because they are not a family member. YIC who are family members, however, are also unsatisfied with the support provided by professionals, because they do not feel it is available at time when they most need it. Consequently, both family members and friends who act as YIC emphasize that they lack appropriate support as YICs of PMI that appeals to them and that is available when they are in need of it.

The evaluation of the web-based and folder support interventions showed that any support is better than no support. It was up to each individual participant to decide whether to use the support offered to them or any other support that might be available. Web-based support, according to the YIC, was something that could improve their caring situation for the better, reduce their stress, and increase their well-being and quality of life.

Implications

The situation of YIC of PMI evinces a need for their care and support, particularly for social support, because of the emotional and instrumental needs that they experience; they need help not only with physical needs, but also with the feeling that they

stand alone in their demanding situation. Nurses and other health care personnel may be able to provide YIC with both, by listening and being present, which is essential to nursing support, in particular to psychiatric specialist nurses, and which is also in line with relational ethics, for which nurses strive in their profession. The main reason for lack of trust in psychiatric health care services is negative encounters with healthcare personnel. Health care personnel in today's psychiatric services need to gain deeper knowledge of how to support young persons who shoulder the daily responsibility of a PMI. Furthermore all healthcare personnel need to be frequently updated with the latest evidence-based knowledge concerning YIC and how to respond to their needs.

The rapid development of eHealth should be an asset to today's psychiatric health care services since this development can open new possibilities for reaching out to the more vulnerable persons in society. Today the citizens demand good and efficient care and the demand for it to be evidence-based is strong. The citizens of today are aware that they are just a few clicks away from the latest information on different health issues and health care has a responsibility to take part in this process.

The nursing education need to introduce eHealth and mHealth knowledge to the students to be able to meet the on-going and future development of society, as research shows more and more people are using the web frequently to search for health-related information and support. Almost everyone in the industrial societies has easy access to eHealth and mHealth, and more persons can be supported through the web. Nursing and other health care curricula are not sufficiently up to date on meeting the rapidly expanding and constantly changing knowledge on eHealth and mHealth. As the internet becomes an ever more fundamental part of life - especially young person's lives - it is essential to provide nurses and other healthcare personnel with modern technological knowledge and skills.

A growing number of research studies, including the papers in this thesis, show that YIC have needs and are lacking appropriate support that targets them as YIC of PMI. In order to develop successful and appropriate supportive interventions for YIC, their needs must be mapped and several issues considered ensuring that the intervention is appropriate. However, there is an alarming need for appropriate professional support for YIC, which needs to be evaluated and considered for future research. As research has indicated that web-based support is not the only solution, this indicates a need for nurses and healthcare professionals to be open to person's own preferences and needs. YIC should be considered as whole individuals, and their histories, everyday lives, and future plans should be taken into account, along with their unique perspectives, personal resources and strengths, and health-related limitations and vulnerabilities.

SWEDISH SUMMARY

Den psykiska ohälsan ökar i hela världen. I Sverige anger 26 procent av alla kvinnor och 16 procent av alla män att de upplever psykiska besvär, såsom oro, ångslan eller ångest. De senaste decennierna har också ungdomars psykiska hälsa försämrats. Eftersom huvuddelen av psykiatrisk vård bedrivs i öppenvård blir de närstående, till exempel föräldrar, syskon, barn och vänner, involverade och får ta ett stort ansvar. Forskning som omfattar närståendes upplevelser i samband med psykisk ohälsa visar att sjukdomen har betydande konsekvenser även för närstående. En grupp av närstående som är utsatta för hög belastning är unga personer som är närstående till någon sjuk familjemedlem eller vän, vilket är denna avhandlings fokus.

Den höga prevalensen av psykisk ohälsa bland unga vuxna gör att deras närstående kan utsättas för påfrestningar, genom att de tar ansvar för att stödja kamrater i svåra livssituationer. De unga kan drabbas då de själva är i en period i livet där de ska ta sig an vuxenlivet. Ett aktivt vardagsliv med skola och fritidsliv samtidigt som den unge ska försöka finna sin väg i livet med allt vad det innebär, så som en karriär eller bilda familj, så kan det bli belastande att ta hand om till exempel en förälder, syskon eller vän som lider av psykisk ohälsa. Idag finns det forskning som visar på hur en familjemedlem till en person med psykisk ohälsa påverkas, men mycket lite om hur det är för unga personer som stödjer vänner med psykisk ohälsa. Denna studie fokuserade på unga närstående personers livssituation, behov av stödjande insatser och på vilket sätt detta kan göras samt utvärdering av web-baserat stöd till dessa unga som lever nära en person med psykisk ohälsa.

Det övergripande syftet med denna avhandling var att få kunskap om hur unga personer, som är närstående och ger stöd och vård till en person med psykisk ohälsa, familjemedlem eller nära vän, hanterar sin vardag. Dessutom syftade denna studie till att utvärdera webbaserade hälsoinsatser, till exempel information och stöd till unga personer som lever nära personer med psykisk ohälsa.

De specifika syftena för varje delstudie var:

- att belysa det dagliga livet för unga vuxna som ger vård och stöd till en person med psykisk ohälsa och hur dessa unga närstående hanterar sin vardag
- att jämföra börda, hälsa, självförtroende och stress hos unga närstående som stödjer en familjemedlem eller en vän med psykisk ohälsa
- att belysa erfarenheter av stöd till unga närstående av personer med psykisk ohälsa, samt att undersöka hur unga informella vårdare använder sig av stöd
- att jämföra effekten av två interventioner, ett webbaserat stöd samt stöd genom en broschyr för unga informella vårdare till personer med psykisk ohälsa. Det primära utfallsmåttet var stress, sekundära utfall var börda, självförtroende, välbefinnande, hälsa och livskvalitet.

Denna studie består av en kvalitativt beskrivande - (I), komparativ - (II), mixad metod - (III), och en experimentell design (IV) studie. Deltagare till studien rekryterades

i två omgångar. I den första rekryteringsprocessen rekryterades deltagare (n=12) till de kvalitativa intervjuerna. I den andra rekryteringsprocessen rekryterades deltagare (n=403) för att ingå i interventionsstudien och deltagarna fick besvara självskattningsformulär innan interventionen (T¹), efter 4 månader (T²) och efter 8 månader (T³) under 2010 och 2011.

Resultatet visar att unga närstående har svårigheter att veta vart de ska vända sig när de behöver hjälp eller stöd. De efterlyser tydligare anvisningar från samhället vart de ska vända sig för att få professionell hjälp eller stöd. Unga vuxna personer som kommer i kontakt med psykiatri tillsammans med sin närstående som lider av psykisk ohälsa, vittnar om att de inte blir sedda eller tagna på allvar. De önskar att bli involverade i den närståendes vård och beslutstagande, eftersom de har värdefull information kring deras närstående. De unga lever nära personen med psykisk ohälsa och känner därför ett ansvar även när denne vårdas på sjukhus.

Unga närstående till personer med psykisk ohälsa saknar professionellt och tillgängligt stöd. De upplever att deras närmaste sociala nätverk inte vet vad de ska säga eller hur de ska bete sig när de delger sina innersta tankar om vad som händer i deras liv som ung närstående. De unga blir inte tagna på allvar av personer i deras närhet när de berättar om sin situation vilket får till följd att de istället vänder sig till personen som är psykiskt sjuk. På så sätt behöver ingen utomstående få veta vad som pågår och de slipper förklara eller göra sig av med energi genom att försöka få någon annan att förstå eller engagera sig. De unga vuxna personerna tror att samtalsstöd, stöd i grupp, information eller stöd via internet skulle förbättra deras situation. De unga vuxna personerna i denna studie visar att de helst vill kombinera personlig professionell kontakt med information som ständigt skall finnas tillgängligt för dem på nätet.

För att kunna möta dagens krav på tillgänglig och effektiv vård och omsorg är det viktigt att utveckla nya metoder för att underlätta känslan av delaktighet. En sådan åtgärd kan vara information och stöd som är tillgänglig via Internet. En grupp unga personer som identifierade sig själva som att de gav stöd till en familjemedlem eller en vän, fick prova web-baserat stöd eller stöd genom en broschyr i 8 månader. Resultatet visade att stressnivån låg högt i både webb- och broschyr gruppen vid start av interventionen, men minskade i båda grupperna. Broschyrgruppen visade en signifikant minskning. Även om stressen minskade i båda grupperna så uppvisar ändå båda grupperna en stressnivå som är jämförbar med andra ungdomar i Europa och som kan betecknas som hög jämfört med andra grupper i populationen.

Denna avhandling visar att unga personer som stöttar en person med psykisk ohälsa hanterar ett ansvar som bör förknippas med vad en vuxen bör hantera. Oavsett om de unga personerna stöttar en familjemedlem eller en vän så blir de påverkade i sitt vardagsliv. Att leva nära och ta hand om en person med psykisk ohälsa innebär för många unga att offra en del av sin egen tid för att finnas till hands för personen som är sjuk. De unga efterlyser mera stöd från inte minst sitt eget sociala nätverk, men även professionellt stöd ifrån samhället som riktar sig till dem. De upplever att det stödet som finns för dem antingen inte är riktat till dem som målgrupp eller så är inte innehållet från någon seriös förening eller instans. De unga vuxna som varit i kontakt med psykiatri tillsammans med den som lider av psykisk ohälsa, vittnar i flera fall om ett olus-

tigt bemötande där de kände sig åsidosatta eller inte blev tagna på allvar. Detta leder i sin tur till att de inte känner något förtroende för vården i allmänhet och psykiatri i synnerhet. De unga efterlyser mer personcentrering i hur de blir bemötta av vården. De önskar bli sedda av de professionella och få vara delaktiga i beslutstagandet kring vad som är bäst för den som är drabbad, eftersom de känner personen ifråga bäst. De unga vänder sig till sitt sociala nätverk först och främst när de är i behov av stöd, och använder sig av internet när de söker efter information. Att utveckla ett web-baserat stöd för unga kan fungera som ett sätt att nå ut till flera som är i en informell vårdarroll och behöver stöd i det. Denna studie har visat på att oavsett vilket stöd som ges, så är det bättre än inget stöd alls. Det är personen själv som utifrån sina behov kommer att använda sig av de stödinsatser som finns tillgängligt för henne eller honom.

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