

Professionals' Opinions on Support for People with Chronic Illness in their roles as parents in Mental or in General Health Care

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Abstract

Chronic illness afflicts a person's wellbeing and affects the ability to perform the social roles of spouse or parent. When working with people with long-lasting mental or somatic illnesses, social workers and nurses are confronted with needs for support, especially for parents. Although programs are in place for the children of parents with chronic illnesses, specific services for the parents themselves are scarce, as are parenting support courses for professionals. In an explorative study we investigated the similarities and differences between mental health organizations and general hospitals in providing support to parents.

Using a cross-sectional design, information on supported parenting was collected through an internet questionnaire. Professionals in general hospitals found themselves more able to provide support to parents than did those in mental health organizations that were not trained in supported parenting. Professionals in mental health institutions generally reported that the attention paid to the parental role is insufficient. However, professionals in mental health organizations who were trained in supported parenting considered paying attention to the parental role more as a part of their job than the participants from organizations without such a training. Further research should expand this first pilot study on the attitude of professionals towards supported parenting.

Introduction

Chronic illness, including some mental illnesses not only afflicts a person's wellbeing but can also have great impact on the ability to perform social roles as a spouse or a parent. Social workers and nurses are confronted with their patients' needs for support and advice, especially when children are involved. The number of parents with chronic illness is relatively

large in mental health care. Research in various high income countries shows that one quarter to over half of the people with severe mental illness are parents. The highest percentages were found in the US and UK: In the US, a study by Nicholson, Biebel, Williams, & Katz-Leavy (2004) reported 67% of people with severe mental illness to be parents whereas Howard, Kumar & Thornicroft (2001) showed that 63% of the women with psychosis in Great Britain have children. In the Netherlands and Australia these percentages are lower, respectively 48% (Van der Ende, Van Busschbach, Wiersma, & Korevaar, 2011) and 25–28% (Howe, Batchelor & Bochynska, 2012) but still substantial. In the general population more than 57% of people between 18-65 years have children (Office for National Statistics, 2011) and the proportion of people in general hospitals with chronic illness who have children is likely to be the same.

In psychiatric research, the challenges faced by parents with severe mental illness have drawn increasing interest (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001; Nicholson et al. 2004; Nicholson & Deveney, 2009; Wansink, Hosman, Janssens, Hoencamp, & Willems, 2014). However, while programs exist for ‘Children of Parents with Mental Illness’ (COPMI, Orvaschel, Walsh-Allis, & Ye, 1988;Stiffman, Earls, Robins, & Jung, 1988; Thomas, Forehand, & Neighbors, 1995; Ackerson, 2003b; Van Doesum, Riksen-Walraven & Hosman, 2008), specific services for parents are scarce, as are programs to train social workers and nurses on how to support people with chronic illness in their roles as parents (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006). The need for care in this area is reflected in a recent study in which half of the responding parents with psychiatric disabilities reported that they wanted types of support that regular mental health care did not supply: for example nurturance support, legal assistance with custody and child support and arranging for support from peers (Van der Ende, Venderink, & Van Busschbach, 2010). However, adequate

social support is not always available because fear of stigmatization often renders the topic off-limits and leads to secrecy and concealment (Hinshaw, 2005; Thornicroft et al. 2009).

In general health care, family-centered care and nurses who attend to the needs of the children are needed (Coyne, O'Neill, Murphy, Costello, & O'Shea, 2011). The importance of the role nurses play is indisputable, especially in the case of chronic or fatal illness, when children must cope with the threat of losing their parental care (Helseth & Ulfsaet, 2005; Huizinga et al. 2005). Parents with cancer have feelings of guilt about not being good parents, and they struggle to know how they should talk to their children about cancer (Semple & McCance, 2010).

However, because the parent is the "patient", the primary attention of health professionals remains focused on him or her (Huizinga et al. 2005). Although a special group program for parents with cancer was developed recently (Hasson-Ohayon & Braun, 2011), the efforts taken to address the psychosocial aspects of living with parental cancer are mostly still in their infancy (Syse, Aas, & Loge, 2012). In this article, the professional support of any aspect of parenting is called "supported parenting." This term does not refer to a special program and it includes the non-systematic support of parents by professionals. Also, all different kinds of parenting are included. It applies to the tasks and skills of parents that share their roofs with their children and have 24 hours responsibility for them but also to the needs of others who only see their children once in a week or less while others have only sparse face to face contact because of long term hospitalization and in the worst case scenario know that because of terminal illness will not see their children grow up.

Information about the need for supported parenting and for special programs can be found in several studies (Göpfert, Webster, & Seeman, 2004; Hinden et al. 2006; Syse et al. 2012). To what extent different professionals in general health care provide this support is unknown. Most of the described programs are family-centered and strength-based, and some

use case management as a starting point. According to the study by Hinden et al. (2006) no programs have been researched in outcome studies, indicating that these programs are not evidence-based. Furthermore, Korhonen, Vehviläinen-Julkunen, & Pietilä (2008) claim that most nurses in general hospitals support the wellbeing of parent patients and talk with them about their children. However virtually no studies can be found on the role of professional workers in supporting parental responsibilities in the context of adult psychiatry (Korhonen, et al. 2008).

This study addresses the question whether hospital staff members provide supported parenting to their patients and especially whether the given support varies between mental health facilities and general hospitals. Different parental support practices are investigated. This was also done with a focus on possible differences between the staff members in organizations who were trained in supported parenting and those who were not. This comparison provides a snapshot of the availability of supported parenting and identifies organizations that can serve as an example for other organizations.

Methods

Participants

The first group (n=41) of respondents in this study comprised of workers in two provincial Dutch mental health organizations where professionals had previously received a four-day training in the parenting support program called PARSS (See Appendix 2 and also Van der Ende et al, 2014). This program is a recovery and psychiatric rehabilitation-based, guided self-help intervention for parents with severe mental illnesses that was inspired by the rehabilitative approach used by the Psychiatric Center of Rehabilitation of Boston (Farkas & Anthony, 1991). The approach comprises a methodology that helps parents explore, choose, and realize their goals in the areas of parenting. Depending on his or her needs and

preferences, a parent in recovery is supported in the parental role in conjunction with different aspects of life such as achieving a balance between holding a job and housekeeping and finding time for rest and recreation. The second group of respondents (n=36) consisted of professionals from two nearby mental health organizations where no such training had been offered. In the four mental health organizations of these two groups, workers from a variety of departments (long stay/short stay, inpatient/outpatient care) were approached. The third group of respondents (n=51) included health workers from three Dutch general hospitals from long-stay departments with specialties such as oncology, pulmonary illness and burns. All organizations were located in the northern part of the Netherlands, which is mainly a rural area with a few larger cities.

Workers from various disciplines responded to the invitations: including 54 nurses, 49 social workers, 9 psychologists, 8 physicians and 8 from other disciplines (see Table 1). No special family therapists were found in this group. In our general hospital sample, most professionals are nurses, while in the mental hospitals more social workers are found.

Table 1 Discipline of the Participants in the Research Group (N = 128)

	Mental health organizations		General hospitals	Total
	trained [#] n = 41	not trained n = 36	n = 51	n = 128
Disciplines				
Social Worker	29 (71%)	8 (22%)	12 (24%)	49 (38%)
Nurse	8 (20%)	11 (31%)	35 (69%)	54 (42%)
Psychologist	1 (2%)	8 (22%)	0	9 (7%)
Physician	1 (2%)	5 (14%)	2 (4%)	8 (6%)
Other	2 (5%)	4 (11%)	2 (4%)	8 (6%)

in supported parenting.

Differences were identified between the organizations with regard to the professional backgrounds of the participants. Social workers who were trained in supported parenting were mainly associated with the mental health organizations in which such training was offered. In

the mental health organizations that did not offer such training, the participants were nearly equally divided among the disciplines.

Measures

To shed more light on how workers think about supporting people with chronic illness in their parental role, a questionnaire was designed specifically for this study. Questions addressed the support given to parenting and the content of the interactions concerning the parental role that occurred between the staff and people with chronic illness. Examples of the questions include the following: “What do you think of the attention to parenting that is paid by your organization”, “Supported parenting is an important topic”, “Supporting parents is part of my job”, “Do you pay attention to the functioning of the children” and “What type of contact do you have with your patients: treatment, support, giving information.

One question about the themes of the support was extracted from an instrument on parenting by Kendall and Bloomfield (2005): “What parental role subjects do you pay attention to?” with the answering categories ‘emotions’, ‘empathy’, ‘social contacts’, ‘tensions’, ‘acceptance’, ‘boundaries’, ‘control’, ‘play with children’, ‘knowledge of services’ and three categories added ‘contacts with services’, ‘balance’ and ‘talk with children’. The respondents were instructed to choose the three items that were most important in the care they provided to parents. In table 3 answers were put together two by two. Scale analysis showed this question on “The content of the contact about the parental role” between professionals and parents to be an acceptable scale with Cronbach's $\alpha = .7$. Next a categorical question was asked concerning why the workers were able to pay attention to parenting with answers such as “enough knowledge” and “competent to offer support”.

At the end of the questionnaire, a few open questions on supported parenting were asked. General information about the department, discipline and characteristics of the people

with chronic illness were also gathered. Questions referring to the characteristics of workers such as age and work experience were omitted to create a brief questionnaire that could be completed in seven minutes on average. Because this was a new questionnaire with an explorative character, the subjects were diverse as were the ways in which the responses were categorized.

Procedure

Several managers of the Hanze University of Applied Sciences had work contacts with managers in the health organizations and after an invitation letter, emails were sent by people from these organizations to the professionals with a request to participate in this study. Selection of organizations was based on whether or not training on supported parenting was offered and the region. All of these centers were nonprofit organizations. After receiving an invitation through email, 128 people completed web-based questionnaires.

Design

For this explorative study, a cross-sectional design with three pre-formed groups of respondents was chosen to explore the differences between general hospitals and mental health organizations in terms of the resources available for supporting parents and the competence of its workers in talking about parenting and giving support.

Analysis

For the statistical analyses, the software program SPSS-22.0 (IBM Corp., 2013) was used to compute Cronbach's α to test reliability of a scale and chi-square statistics to compare responses among the groups. The Bonferroni correction was used to counteract the problem of multiple comparisons.

Results

Support for Parental Role

The first part of Table 2 shows how respondents perceived their organizations' attitudes toward parental support, in answer to the questions like: "What do you think of the attention to parenting that is paid by your organization" and "Is the support seen as a part of the job?" The second part of the table shows how competent they felt as professionals to provide parental support.

Table 2 Perceptions of Supporting Parents (% confirmative answers) N=128

	Mental health organizations		General hospitals
	trained ^a	not trained	n = 51
	n = 41	n = 36	
Organization			
Organization pays enough attention to parenting	25 (61%)	9 (25%)	37 (73%)* ¹
Parenting is an important topic	16 (39%)	11 (31%)	18 (35%)
Enough time is provided to support parents	13 (32%)	2 (6%)	19 (37%)* ²
Supporting parents is part of my job	30 (73%)	22 (61%)	26 (51%)
Professionals			
Enough knowledge on supporting parents	13 (31%)	9 (25%)	11 (21%)
Competent for supporting parents	20 (49%)	12 (33%)	26 (51%)

Note. The p-values were checked with Bonferroni's multiple comparison calculation

*1. $\chi^2 = 20.0$ df = 2 p < .001

*2. $\chi^2 = 11.7$ df = 2 p = .003.

^a in supported parenting.

Perceptions of supported parenting

In the general hospitals, 73% found that their organization paid sufficient attention to parenting. In the mental health organizations where training in supported parenting was given, 61% of the professionals stated that their organization adequately facilitated parental support. However, in mental health organizations without such training, significantly fewer

professionals, 25%, felt that their organization paid enough support to the parental role of patients.

No differences between organizations were found in the importance of the topic: of all the participants, 31% to 39% rated supported parenting as one of the three most important topics. In comparisons with the other groups significantly fewer professionals from the mental health organizations without specific training reported that they had enough time for this type of support. Over 50% of the professionals surveyed stated that at their organizations, supported parenting was considered part of their jobs, and there were no significant differences between groups in this respect.

Competence in providing supported parenting

When the participants were asked why they discuss parenting with chronically ill patients, in an open-ended question some answers were included: “We offer the whole package, and caring for people with chronic illness can’t be done without paying attention to the children,” and “If a parent is limited in handling their children, we make it a part of their treatment plan.” Reasons for not discussing parenting were related to time or to the fact that the parents had no unmet needs in this area. Furthermore, the respondents noted some special reasons for participants not to discuss this subject. One respondent wrote: “Parents in general do not express that they have problems with parenting. The focus is more on the actual problems.” Another participant wrote: “The parent will be referred to a family-therapist or to another organization, such as Children and Youth Services.”

There were several answers to the question about why professionals felt they provided adequate supported parenting. At the mental health organizations that trained their staff in supported parenting, 31% of the participants reported that they had sufficient knowledge to

provide supported parenting. This percentage was lower in the mental health organizations without training and in the general hospitals (25% and 21%, respectively).

Respondents also reported that competence was a reason why they provided adequate supported parenting. Forty-nine percent of the staff in the mental hospitals with past training and 51% of the staff in the general hospitals indicated they felt competent as compared to 33% of the staff in the mental hospitals with no past parental support training.

Type of contact

Table 3 shows the type of contact between the mental health worker and the parent, for example, as part of treatment or informative.

Table 3 Type of Contact in Supported Parenting by Health Workers (% confirmative answers) N=128

	Mental health organizations		General hospitals	
	trained# n = 41	not trained n = 36	n = 51	
Type of contact				
Treatment	31 (76%)	20 (56%)	34 (67%)	
Support	16 (39%)	14 (39%)	32 (63%)	
Providing information	4 (10%)	1 (3%)	7 (14%)	

Note. Numbers in parentheses indicate column percentages.

in supported parenting

No significant difference between the organizations was found in the amount of treatment-orientated versus support-oriented contact reported. General information about parenting was provided by 3% to 14% of the workers. Supported parenting was described by some of the participants as part of the treatment plan aimed at recovery; however, others classified supported parenting as a form of general supportive care to help people with chronic illness cope with everyday life.

Content of Contact

Table 4 shows the different subjects that were discussed by professionals with patients who are parents and gives an impression of the content of the contacts between health professional and these parents.

Table 4. Content of Contact in Supported Parenting by Health Workers (% confirmative answers) N=128

	Mental health organizations		General hospitals	
	trained# n = 41	not trained n = 36	n = 51	
Content of contact *				
Emotions and empathy	18 (44%)	15 (42%)	33 (65%)	
Social contacts and balance	24 (58%)	18 (50%)	18 (35%)	
Tensions and acceptance	18 (44%)	13 (36%)	24 (47%)	
Boundaries and control	23 (56%)	18 (50%)	13 (25%)**	
Play and talk with children	18 (44%)	14 (39%)	23 (45%)	
Knowledge and contacts with services	20 (49%)	8 (22 %)	12 (24%)	

Note. More than 1 answer per person was possible. Numbers in parentheses indicate column percentages. The p-values were confirmed with Bonferroni's multiple comparison calculation

in supported parenting

*Cronbach's $\alpha = .7$

** $\chi^2 = 10.0$, $df = 2$, $p < .001$

“The content of the contact about the parental role” between professionals and parents offered an acceptable scale (with Cronbach's $\alpha = .7$) in this study. Most support for parents was aimed at promoting emotional connections with the children. Subsequently, professionals addressed subjects related to upbringing, such as setting boundaries and control. Possibly because of the differences in the needs of the parents at hand, staff in the mental health organizations, paid significantly more attention to these subjects, compared with the participants from the general hospitals. There was a significant statistical difference for the variable ‘boundaries and control’ among these settings. In general hospitals most professionals are nurse, while in the mental hospitals more social workers are found. This significant difference may have occurred due to the different professional identities of these

staff members, but no other significant differences in supported parenting were found between these disciplines.

Discussion

In all participating mental health organizations and general hospitals more than one third of the workers who participated in the survey rated supported parenting as one of the three most important topics. Although this survey was not an evaluation of the staff training (that was conducted in another study, Van der Ende et al. 2014), some tendencies were apparent. Participating professionals in settings with previous training had more knowledge and felt as competent as the workers in our sample in the general hospitals and more competent than those in the mental health organizations without training.

The study indicates that supporting the parental role is possibly less present among the professionals in mental health organizations than in general hospitals and this was opposed to what we expected. In the mental health organizations where training in supported parenting was provided, over half of the participants stated that they had adequate time for supported parenting, whereas in untrained mental health organizations, significantly fewer participants could find time to pay attention to the parental role.

The primary attention of mental health professionals in our sample appeared to be focused on the person with a chronic mental illness; support for the parenting tasks was not generally a component of patient care. More than these respondents, those in general hospitals focussed not only on the physical health of the patients but also on the children and parenting in cases of serious and long-term problems. In terms of benchmarking, the general hospitals seem to have a lot to offer in ways of supported parenting.

The strength of this study is that it describes a wide variety of health workers' possibilities and competencies for supported parenting and the influence of the context and

training on supported parenting. No previous reports have directly compared general hospitals and mental health organizations.

A selection bias may have contributed to these results. Respondents from both types of mental health organizations and the general hospitals could have chosen to participate in this study because they had a preexisting interest in supported parenting. A more random inclusion could have led to different results. A selection bias may have contributed to these results and limits their generalizability. Respondents from both types of mental health organizations and the general hospitals could have chosen to participate in this study because they had a preexisting interest in supported parenting. A more random inclusion could have led to different results. For now this study should be regarded as a first explorative study and with only limited value where the opinion of other professionals in the same or other hospitals are concerned. For practical reasons, additional information concerning the characteristics of the respondents was limited to their work environment. By thus omitting individual characteristics such as age and work experience, we are unable to determine how such characteristics may have influenced responses and consequently, the results of the study. New studies are required to determine whether the significant differences exist in larger representative samples, too.

The possibility of bias is particularly strong because the study was conducted through a web-based internet questionnaire. Since emails with invitations to participate were spread in the organization no random selection but a self-selection by participants took place. The liabilities associated with samples obtained from the internet are not likely to be much greater than the weaknesses associated with traditional recruitment methods, such as the trade-off between internal validity and generalizability (Lieberman, 2007). The results of a study by Gosling, Vazire, Srivastava, & John (2004) suggested that valid and reliable data can be obtained when the population is accessed via the internet. Currently, doubts exist concerning

the generalizability of the outcomes of this type of research. Because online scientific studies do not belong to an established research tradition, additional techniques must be developed to gain insight into variables such as non-response and the bias caused by selecting patients who are 'online'. However, the cited articles indicate that the results of online research can be generalized with the same cautions applicable to other types of research in which no absolute response is guaranteed. Although information about the non-participants is missing, internet-based findings are consistent with findings based on traditional methods (Walker, 2013).

Another limitation was the use of an unvalidated questionnaire for this online study because no validated instruments were available. To promote a greater number of responses, the new questionnaire was quite short. Because the study was a descriptive pilot, only nominal data were gathered. Validity was augmented by the fact that professionals could answer anonymously.

No insight was obtained on possible differences between male and female professionals with regard to supporting their patients' parenting. In general hospitals most professionals were nurses, while in the in supported parenting trained mental health organizations more social workers were found and the other mental health organizations had an equal number of these disciplines. No significant differences on all variables were found between nurses and social workers. Still the distribution of disciplines of workers might have been a confounding factor.

The conclusion from this small explorative study that supported parenting was insufficiently available in mental health organizations in the Netherlands contrasts with research findings from Finland, where more than 90% of the nurses in the psychiatric units of five Finnish hospitals took the initiative to talk about children with their patients and were aware of the importance of a family support network and a stable family environment (Korhonen, Vehviläinen-Julkunen, & Pietilä, 2010). Our study however gave evidence that a

training in supporting the parental role in mental health organizations can give a contribution to parental support in the eyes of the professionals. After all we did find that professionals from mental health organizations who were trained in supported parenting described it as part of their job more frequently than did the participants from organizations where no such training was provided. Professionals in mental health organizations generally found the attention paid to the parental role to be insufficient. However, professionals from mental health organizations who were trained in supported parenting described it as part of their job more frequently than did the participants from organizations where no such training was provided. This might give evidence that a training in supporting the parental role in mental health organizations can give a contribution to parental support in the eyes of the professionals. Several supported parenting programs for care providers have already been developed (Hinden et al. 2006; Reupert & Maybery, 2009; Van der Ende et al. 2010), which could be implemented by existing facilities. Recently, a program was developed that focuses on both parents and children (Wansink et al. 2014). In addition, internet programs are available (Kaplan, Solomon, Salzer, & Brusilovskiy, 2014).

As for now this study indicates that the specific parenting support needs of patients with chronic illnesses are possibly better met in general hospitals than in most mental health centers. In these organizations, training professionals in supported parenting can have a positive influence on the amount of attention paid to the challenges patients face as parents.

To complete this research, quantitative and qualitative data will be needed about how parents with mental illness, both fathers and mothers, experience and reflect on the available professional support. Further research should expand this first pilot study on the attitude of professionals towards supported parenting with a representative sample of both social workers and nurses, focusing on the influence of training on competence and actual behavior.

The mental health organizations are advised to make supported parenting available to all patients who need it and to provide staff with sufficient competencies in this type of support. Individual care plans should be designed to include support for parents. In this plan the personal network and professional workers in an outpatient setting after the parent's discharge should also be involved in the parents' care.

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