

# Caregiver experiences of nursing care for their hospitalized relative due to mania.

Student	Testerink A.E.
Student number	4192516
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Supervisor	Prof. dr. Peter J.J. Goossens, Dimence group, Deventer
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## Introduction

Bipolar disorder (BD) is a severe mental illness. There are two major types of BD (1): BD type I includes manic, depressed, and hypomanic episodes (1), while in BD type II, only depressed and hypomanic episodes occur (1). Mania is characterized by elevated mood and three or more mania-related symptoms. Hypomania is similar to mania, but fewer than three symptoms occur and functional decline is less severe (1, 2). Most patients need multidisciplinary treatment on acute, closed psychiatric wards (3). As a result of the poor perception of illness and a problematic behavior, hospitalization is often involuntary (3). Nursing care for patients during mania on acute, closed psychiatric wards consists of demonstrating boundaries, optimizing medication compliance, administering medication, and providing structure and supportive communication (4).

Bipolar disorder affects the lives of patients and caregivers (5, 6). During manic episodes, patients often argue with and criticize those around them, who try to help, such as caregivers (7). As a result of their relationship, caregivers are involved in patients' treatment during hospitalization (7). Caregivers report a moderate to high level of burden during the patient's hospitalization, though in this study, only 1.8% of the sample consists of patients during mania (5). Nurses are reported as the persons from whom caregivers would like to gain more support (8, 9). The spouses of patients with BD experienced disregard when their partners were hospitalized (10). Caregivers reported that the information about the manic episode that was provided during hospitalization was inadequate (9). The lack of information creates frustration for caregivers and may cause them to feel alienated from both healthcare services and their relative (9, 10). Nurses experience a dilemma of loyalty when they are confronted with conflicting interests between patients and caregivers (7), due to professional secrecy (9). Information about the patient may only be disclosed to third parties with the explicit permission of the patient (11). Nurses experience a lack of time for offering support and information to caregivers, due to secondary or non-nursing tasks (4).

The literature currently lacks considerations into caregivers' experiences regarding the nursing care that is received by their relatives during hospitalization due to mania. Literature focuses on caregiver experiences regarding patients with BD, without specifying mania. Furthermore, prior research focuses on the experiences of caregivers before admission. This information is necessary because of the complexity of the relationship and of the behavioral changes during mania. By gaining insights into caregivers' experiences, the nursing care for patients with BD during mania may be improved.

## **Aim**

The aim of this study is to gain insight into the experiences of caregivers regarding the nursing care which their relatives receive during hospitalization due to mania, on acute, closed psychiatric wards.

## **Method**

A descriptive phenomenological research design was carried out in order to gain insight into caregivers' perspective on nursing care, by exploring the meaning of their lived experiences (12, 13).

## **Population and sampling**

Participating caregivers were required to be caregivers of patients with BD who were hospitalized on acute, closed wards during the last year, due to mania. From the patients' perspective, a caregiver is an important person in their lives, who is not a professional, and who delivers significant support and care for the patient (14, 15). A convenience sample based on accessibility and caregivers' willingness was conducted (16). All caregivers needed to be able to read, understand and speak Dutch. To avoid information bias, caregivers were excluded from participation in this study if they met one of the two exclusion criteria: having been hospitalized on a psychiatric ward in the past five years, or being professionals on a psychiatric ward at the time of recruitment or during the previous ten years (17).

## **Recruitment**

Caregivers were recruited from three mental health organizations in The Netherlands and was done by giving clinicians oral and written information about the study. During the same period, Van Lankeren et al. (2016) studied the experiences of patients regarding the nursing care they received during hospitalization due to mania, and clinicians inquired if patients were willing to participate in their study. Those participants were then asked whether they had a caregiver who may be interested in participating in this study. The second method of recruitment was via the internet forum of the Dutch Association for patients with bipolar disorder and caregivers (DABDIC), in which caregivers were asked to participate in this study. Willing caregivers received oral information over the phone and written information by email. After a week, caregivers were contacted again and questions were answered, and if the caregiver wanted to participate, the interview was planned. Before the interview started, additional questions were answered and an informed consent was signed.

## **Data collection**

Data collection took place through open in-depth interviews. Data were collected between February 2016 and May 2016. Interviews were carried out at the caregiver's house, or at the out-patient clinic in which the relative received treatment at the time of the interview. An aide-memoire was used to enable flexibility in following the participants accounts of their experiences during the interviews (18, 19). This aide-memoire consisted of several literature-based topics and was conducted under the supervision of the second author (Appendix 1). The interviews all began with the same question: "Can you give me an example of the nursing care that your relative received during his/her last hospitalization due to mania?" Follow-up questions were based on the information that the caregiver provided. All of the interviews were audio-taped and transcribed verbatim. An audit trail about the data-collection process was maintained and, in order to improve the transparency of the results, a logbook of memos was kept during the entire research process.

## **Data analysis**

Data was analyzed using the Stevick-Colaizzi-Keen method (table 1) and NVivo 11 (20). Bracketing was conducted in a reflective journal, by using memos in the logbook. After reading and re-reading, open coding was done, followed by axial coding, which was done by conducting meaning units, and textual and structural descriptions. The final step was selective coding, which resulted in a description of the essence of the lived experiences of the participants. In order to provide a thick and rich description with valid results, the iterative process of data collection and analysis continued until data saturation was reached: when no new codes were found during the analysis, for at least two interviews (12). In order to strengthen the findings, the essence was sent to all caregivers for a member-check, the caregivers were asked whether the essence was trustworthy regarding their experiences, and participants were informed that if they did not respond to the member-check, it would be assumed that findings were trustworthy.

*Insert table 1*

## **Ethical considerations**

This study was conducted according to the principles of the declaration of Helsinki 2013 (21) and in accordance with the Medical Research Involving Human Subjects Act (22). All scientific committees of the participating organizations gave their approval for conducting the study.

## Results

Nine caregivers were recruited for participation in this study, eight of whom were recruited via the mental health organizations and one of whom was recruited through DABDIC. Caregivers consisted of parents, partners, a friend and a sister of patients with BD. Five of the caregivers were male. Table 2 presents the characteristics of caregivers. During the analysis of the last three interviews, no new codes emerged, thereby reaching data saturation. The results revealed that the caregivers' experiences regarding nursing care focused on three major themes: nursing interventions, nurses' attitudes and the involvement of caregivers.

*Insert table 2*

### Nursing interventions

Due to the limited time during which they were present on the ward, caregivers mentioned that their experiences with nursing interventions were minimal.

*"I cannot accurately judge the nursing, because I'm not there all day." P1*

Despite this, the caregivers expressed a great deal of respect for nurses and were well aware that nurses constantly cared for their relatives.

*"It seems to me that it's really the nurse who, despite all patients' quirks, guides her toward a certain direction." P4*

Caregivers described two nursing interventions: providing medication and limitation on behavior.

*"The nurses provided medication, that's a clear nursing task." P5*

*"The nurses did limit him, they had to limit him on everything." P7*

The experiences of caregivers regarding medication provision vary. Caregivers saw that nurses provided medication, which was experienced as necessary in order to calm the patients during crises.

*"She needs to calm down, in my opinion medication is required." P1*

In the stage after the crisis, during hospitalization, patients were more responsible for themselves, though some would smuggle their medication to throw it away. Caregivers informed nurses about this phenomenon and experienced more monitoring of the patient during medication provision.

*“When she came out of seclusion, she got the medication and then she waited until the nurses were away and then she chucked out the medication.” P3*

Some caregivers found that patients were suspicious and frightened of the nurses during medication provision.

*“It was not clear that it was the nurse who gave her the medication and she was so afraid of being poisoned.” P5*

Caregivers described the limitation on behavior as consisting of seclusion, limitation in setting and limitation on stimuli. Seclusion was experienced as necessary for the protection of the patients or their environment.

*“She was secluded for over a week. She remained manic and aggressive. She was too restless to stay among the other patients, in order protect the others.” P3*

One caregiver experienced anger when his partner was secluded after he had explicitly requested not to seclude, based on prior experiences.

*“For me it is not to judge if seclusion was necessary. However, I can judge my own anger because we agreed not to seclude, she really did not want it.” P5*

Regarding the limitation in setting, caregivers experienced that nurses had an important role in determining the patients' constraints for leaving the ward. For some caregivers, it was not obvious who was responsible for the patient if the patient left the ward.

*“You can just pick her up, she says hello and goodbye. Then I'm not sure if I have responsibility now or not?” P8*

Others mentioned they could make arrangements with the nurses about responsibilities when they took the patient off the ward.

*"It was possible to make agreements about leaving the ward. I know her the best and that is what I told the nurses." P6*

Caregivers also experienced a lack of limitation of stimuli on the ward, for instance regarding eating habits, television access and usage of internet devices.

*"I asked the nurses how it was possible that patients had access to internet, when they were posting all their thoughts on Facebook." P7*

### **Nurses' attitudes**

The caregivers' experiences of nurses' attitudes varies from excellent to highly negative attitudes. How caregivers experienced nurses' attitudes depends on the communication, both with the patients and among themselves.

*"I was really impressed how he approached her and approached us, so we were really lucky with him!" P4*

Caregivers described nurses who had negative attitudes toward their relatives as lacking passion in their work. Others pointed out that it was the nurses' own choice to become a nurse on an acute closed ward and that they should therefore act accordingly.

*"I missed passion, some nurses seemed to be stuck in a rut." P7*

In the experiences of caregivers, nurses' attitudes were correlated to personal attention and to the presence of nurses on the ward. Caregivers' experiences of nurses' personal attention toward their relatives were based on what they had heard from the patient.

*"Nurses have conversations with him, he is very satisfied about the attention. He told me he had a good relationship with some of the nurses." P9*

Those conversations never took place while the caregivers were visiting the patients. Many caregivers described personal attention toward the patient as very good and some even experienced that nurses had attention for the caregivers. On the other hand, some caregivers were left wondering if hospitalization was at all helpful due to the lack of personal attention on the ward.

*"They paid attention to my partner, real attention." P5*

The common experience of the nurses' presence was that they were always sitting at their post, behind computers or drinking coffee. Caregivers reported that they missed the presence of nurses on the ward, which they experienced as low, and claimed that they therefore did not know whether the patient was on the ward. One caregiver mentioned that if nurses were present on the ward, they were always watching television.

*"When I came to visit her, I asked the nurse were my friend was, she didn't know." P2*

*"Nurses were sitting on their post; almost every time they were drinking coffee together or watching television on the ward." P8*

Caregivers also spoke about the recognisability of nurses. On some wards, nurses were required to wear name badges, but not all nurses did so. On other wards, there was no visible difference between nurses, patients and visitors. One caregiver advocated for the reintroduction of uniforms. Caregivers believed that the recognisability of nurses increases the feeling of safety on the ward, for both patients and caregivers.

*"She knew two nurses from prior hospitalizations. It really helps to feel comfortable on the ward when she recognizes the nurses." P6*

### **Involvement of caregivers**

Caregivers were ambivalent about their experiences regarding the participation and involvement in care during their relatives' hospitalization. Caregivers needed rest after the period of evolving mania and therefore assigned the responsibility for their relatives to nurses.

*"They are responsible now, keep me informed, but do not burden me!" P3*

Caregivers informed nurses about patients' behavior and how to react to it, but nurses did not act as requested, which reduced the confidence in nursing care.

*"I told them what to expect from here during the first days, and asked them to call me, so I can speak with her. It turned out the way I expected. However, the only part I regret is they did not call me." P5*

Some caregivers were involved on their own request, while others were approached by nurses to become involved.

*“The nurse said to her, if you want to, your partner can stay the night, without checking with me beforehand. Then I felt I let my partner down.” P4*

Caregivers wanted to be involved, but did not know how to become involved or what they could do. Caregivers wanted continuous fine-tuning of the possibilities and needs, for themselves, their relatives and the ward.

*“Patterns in bipolar disorder are always different, therefore, it is important to work together, I think it is really important.” P3*

Caregivers mentioned that being informed about their relatives is an important feature in their involvement. Partners always received information, be it initiated by nurses or by themselves.

*“If I asked about my wife, I always got information. They didn’t contact me to tell about my wife.” P1*

Caregivers received information if they asked for it themselves. One parent, who was designated by the patient as the first contact, did not receive information from the nurses. He was referred to the clinician for information, on the basis of the Dutch medical treatment act.

*“I have tried to get information from the nurses, but they did not provide any information because of privacy. Instead they referred me to the psychiatrist.” P9*

Caregivers experienced that the provision of information about major treatment decisions, such as translocations, discharge, escalation or seclusion came too late. This occurred despite the fact that such choices would directly affect caregivers and that they wished to be involved in the decision-making process. Information was not always provided by the involved nurse, though caregivers wanted to receive information directly, even in the middle of the night.

*“After dismissing, she came back home and for that moment I had the same problems as before, the only thing changed was her using medication.” P1*

In most cases, partners experienced that nurses cared for them as well and experienced this as positive. Nursing care for caregivers consisted of offering advice about visiting, being generally supportive and offering to talk about the situation.

*“If I wanted to talk with nurses, they really took time for me.” P5*

Nurses always asked if caregivers had children living at home and if so, offered supportive groups for their children. Most caregivers chose not to let their children participate in groups, due to prior experiences.

*“The nurses asked me every time about our children.” P6*

One partner experienced a lack of support from nurses.

*“I felt left alone by the nurses during the hospitalization.” P7*

Caregivers felt free to accept nursing care and if they did not want to receive it, could explain why.

*“As caregiver you were not the patient, but you were involved, and therefore sometimes a patient.” P4*

## **Discussion**

This study offers insight into the experiences of caregivers regarding the nursing care which their relatives received during their hospitalization due to mania. Furthermore, it provides insight into experiences of caregivers' involvement on acute, closed psychiatric wards. Caregivers started the interviews with the idea that they had little experience regarding the care that their relative had received from nurses. This was due to their rare presence on the ward and to the experiences of the low presence of nurses on the ward. Caregivers' experiences consisted of what they saw: they had no clear view on the function of nursing in treatment during hospitalization. Caregivers' experiences regarding nursing care focused on three major themes: nursing interventions, nurses' attitudes and caregivers' involvement.

The themes that were found in this study were consistent with nurses' own perceptions of nursing care for patients during mania (4). The themes were found to be interrelated. Though Chambers found that mental health nurses were positive about mental illness (23), this was

studied within the population of mental health nurses themselves. The results in this study show ambivalence in the experienced attitudes of nurses toward patients.

Caregivers experienced a need for rest for themselves after a high burden during the days prior to their relatives' hospitalization. In order to receive rest, they wanted their relatives to recover from mania and calm down. In caregivers' experiences, medication could help and the limitation on behavior is necessary. Daggenvoorde states that nurses constantly consider what is good for the environment and which limitations patients need (4). Most patients with mania require short-term treatment with medication on a closed ward (24) and nurses are the professionals who provide medication. The limitation on behavior is needed during hospitalization and nurses are involved in limitation as the executive persons (3). However, though these interventions are well studied and are daily practice, in caregivers' experiences nurses sometimes fail in performing these interventions.

Most of the caregivers wanted to be involved in the treatment, to receive information about their relative and for nurses to care for them as well. It is widely acknowledged that the involvement of caregivers in their relatives' treatment during hospitalization has a positive effect on patients' outcomes (3-7, 14, 25, 26). However, based on the results of this study, it appears that partners were more involved than other caregivers. Additionally, the provision of information was experienced differently by partners and other caregivers, and can occur as a result of not knowing how to become involved or what the possibilities of involvement are. McCann identifies this phenomenon for caregivers who are young people, for first-episode psychoses resulting from being excluded from deliberation during hospitalization and for patients who request to maintain confidentiality regarding their treatment (27). This population can be compared to that of the current study because of the similarities in patients' behavior toward caregivers. Beentjes describes that nurses experienced a dual loyalty regarding the interest of the patient and that of the caregivers, and that they needed to break the law in order to provide the caregivers with information (7). Sabanciogullari found that nurses provided only 4.7% of the information that nurses should provide (28). In their study, they found that the provision of information depends on the professional rapport with the caregivers (28). Similar results were found in the current study regarding the relationship between nurses' attitudes and the involvement of caregivers. When caregivers had negative experiences with nurses' attitudes, they were less positive about becoming involved.

Partners mostly experienced support from nurses, whereas other caregivers did not. In the literature, being supportive and providing information to caregivers is a duty in nursing care

(24, 25). However, Tranvåg found that partners of patients with BD were also ambivalent in how they experienced nurses' support toward them (10).

### **Strengths & limitations**

In order to enhance the trustworthiness of this study, the criteria of Lincoln & Guba (1985) were taken into account (18, 29). Dependability was improved by recruiting caregivers in four different organizations across The Netherlands. The results can therefore be generalizable within The Netherlands. However, they are limited to the population of caregivers in The Netherlands and need to be confirmed for other nationalities, due to cultural and organizational differences within healthcare. The data analysis was discussed between the first and second author until a consensus was reached, in order to improve the dependability of the results. In order to strengthen the credibility, a member-check was performed, only one participant responds positive, form the other eight participants is assumed they agree with the results. The confirmability was improved by bracketing by the first author, by keeping a logbook with memos and by keeping an audit trail of the entire process of the study. In order to strengthen the authenticity of the results, quotes were used to illustrate the lived experiences of caregivers. A limitation in the study is that convenience sampling may have caused only willing caregivers to participate. It is unclear whether the present results can be generalized for all caregivers of patients with BD type I, making the results less transferable.

### **Conclusion**

Caregivers had little experience regarding nursing interventions and do not have a clear view of nursing care. Furthermore, experiences differed between partners and other caregivers. Partners are more positive regarding nurses' attitudes and the involvement of caregivers, while other caregivers feel left out. Positive experiences with nurses' attitudes resulted in positive experiences of the nurses' involvement.

### **Recommendations**

There should be no difference in nurses' approaches toward partners or other caregivers. Nurses should be more transparent about which care they provide and on what basis they make their choices in daily care. In their deliberation with caregivers, nurses should listen to caregivers' experiences, advise them on how to care for their relatives and ask them about their expectations regarding nursing care.

Future research should consist of conducting a Delphi study in order to reach consensus between caregivers, patients and nurses on how to involve caregivers during the hospitalization of their relatives due to mania.

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## Tables

Table 1: Stevick-Colaizzi-Keen method of data analysis

Step	What and who	Result
Bracketing	The first author (AT) described all of the personal experiences, beliefs and opinions regarding nursing care of patients who were hospitalized on an acute, closed ward due to mania.	A reflective journal which was discussed with the second author (PG).
Significant statements (open coding)	After reading and rereading the transcripts of the interviews, AT extracted the statements which pertained to the experiences of the caregiver for all interviews. PG extracted significant statements for interviews one, two and six.	A list of all significant statements sorted by interview. For the three interviews from which both AT and PG extracted significant statements, the statements were compared and discussed until consensus was reached.
Meaning units (axial coding)	Based on the significant statements, the meaning units for all data were conducted by AT.	A list of meaning units of the common experiences of all caregivers.
Textual description (axial coding)	AT wrote a description of what caregivers had experienced.	The description of what caregivers had experienced.
Structural description (axial coding)	AT wrote a description of how caregivers had experienced that which they had experienced.	The description of how caregivers had experienced that which they had experienced. Both the textual and the structural descriptions were discussed between AT and PG until consensus was reached.
Essence (selective coding)	AT extracted the essence of what and how caregivers had experienced the nursing care which their relatives had received during hospitalization due to mania.	A condensed description of the common experience of caregivers.

Table 2: Characteristics of caregivers

Caregiver	Gender	age	Relation to patient	Gender of patient	Age of patient	Time since the last hospitalization (months)
1	Male	38	Partner	Female	44	6
2	Female	28	Friend	Female	42	5
3	Male	50	Partner	Female	53	11
4	Female	57	Parent	Female	27	8
5	Male	56	Partner	Female	54	4
6	Male	53	Partner	Female	43	4
7	Female	43	Partner	Male	46	11
8	Female	50	Sister	Female	49	11
9	Male	62	Parent	Male	33	1

## Samenvatting

**Ervaringen van mantelzorgers met betrekking tot de verpleegkundige zorg die hun naasten hebben gekregen tijdens een opname op een gesloten afdeling vanwege een manie.**

### Achtergrond

Bipolaire stoornissen zijn ingrijpende psychiatrische ziekten. Tijdens een manie, moeten patiënten, vanwege gebrekkig ziekte-inzicht en probleemgedrag, vaak opgenomen worden op een gesloten psychiatrische afdeling. Het probleemgedrag veroorzaakt ook relatieproblemen tussen patiënt en mantelzorger, zoals uitputting van de mantelzorger. Tijdens een opname krijgt de patiënt behandeling, onder andere door verpleegkundigen. Verpleegkundige zorg bestaat uit begrenzen, de zorg van medicatie, structureren en het gebruik van steunende communicatie. Het is nodig om de ervaringen van de mantelzorgers te kennen om zo een beter afgestemde zorg te kunnen geven aan de patiënt.

### Doelstelling

Het doel van het onderzoek is om inzicht te krijgen in de ervaringen van mantelzorgers met betrekking tot de verpleegkundige zorg die hun naasten hebben gekregen tijdens een opname op een gesloten afdeling vanwege een manie.

### Methode

Een fenomenologisch onderzoek is uitgevoerd. Data is verzameld aan de hand van open diepte-interviews. Voor de analyse is de Stevick-Colaizzi-Keen methode gebruikt.

### Resultaten

Negen mantelzorgers hebben deelgenomen aan dit onderzoek. De mantelzorgers waren: partners, ouders, een zus en een vriendin. Er werden drie hoofdthema's gevonden: verpleegkundige interventies, attitude van de verpleegkundigen en betrekken van de mantelzorger bij de verpleegkundige zorg.

### Conclusie

Er is een verschil in ervaringen tussen partners en andere mantelzorgers. Partners zijn over het algemeen positiever over de verpleegkundige zorg. Opvallend is dat een positieve houding van de verpleegkundige een positief effect heeft op de betrokkenheid van de mantelzorgers.

### Aanbevelingen

Geef zorg op maat die voldoet aan de behoeften van zowel de patiënt als mantelzorger. Betrek de mantelzorger tijdens de opnameperiode, zij kennen de patiënt. Vervolgonderzoek moet zich richten op hoe verpleegkundigen mantelzorgers moeten betrekken bij de zorg.

### Sleutelbegrippen

Manie, mantelzorger, verpleegkundige

## **Abstract**

### **Caregiver experiences of nursing care for their hospitalized relative due to mania.**

#### **Background**

Bipolar disorder is a major mental illness. Bipolar disorder type I includes manic episodes and has a lifetime prevalence of 0,6%. During mania, patients often need hospitalization on acute, closed psychiatric wards. Poor illness perception and problematic behavior causes relational problems and exhaustion of the caregiver. During hospitalization, patients receive treatment, including nursing care. Nursing care consists of limitation, provision of medication, structuring and supportive communication. It is necessary to have insight into caregivers' experiences with nursing care in order to be able to adjust it to patients' needs.

#### **Objectives**

The aim of this study is to gain insight into the experiences of caregivers concerning the nursing care for their relatives, who suffer from mania.

#### **Methods**

A descriptive phenomenological research design was carried out. The data-analysis consisted of the Stevick-Colaizzi-Keen method.

#### **Results**

Nine caregivers participated in this study. Caregivers were comprised of partners, parents, a sister and a friend. Three major themes were identified: nursing interventions, nurses' attitudes and caregivers' involvement regarding nursing care. Nursing care was positively reviewed by partners, which stands in contrast with the experiences of other caregivers.

#### **Conclusion**

Caregivers had little experience regarding nursing interventions. Experiences differed between partners and other caregivers. Partners are more positive regarding nurses' attitudes. Positive experiences with nurses' attitudes resulted in positive experiences in nurses' involvement.

#### **Recommendations**

There should be no difference in nurses' approach toward partners and that toward other caregivers. Nurses should deliberate with caregivers about nursing care, advice and expectations. Future research should focus on how to involve caregivers.

#### **Keywords**

Mania, nurses, caregiver

## Appendix 1 Aide-Memoire

- 1) **Patient outcomes:** Caregiver burden also influences patient outcomes during the patient's hospitalization (5, 14, 26).
- 2) **Information:** Caregivers reported inadequate information about their family members and multiple studies show the importance of providing informal caregivers with adequate information about the patient (3, 7, 9).
- 3) **Participation:** Patients on acute, closed psychiatric wards were positive about the participation of informal caregivers. However, patients with mania often argued with and criticized caregivers (3, 4, 7).
- 4) **Burden:** Caregivers reported burden due to hospitalization and due to the symptoms of the manic episode (4-7, 14, 26, 30, 31).