

1 **Title page**

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3 **The coping and support needs of incurable cancer patients**

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2 **The coping and support needs of incurable cancer patients**

3 **Abstract**

4 The purpose of this study was to describe the coping processes and support needs of
5 incurable cancer patients. The study was conducted as a qualitative study. The research data
6 were gathered by conducting thematic interviews with outpatients with incurable cancer
7 (n=16) and analyzed by means of inductive content analysis. The results of the study indicate
8 that the lives of patients were temporarily interrupted by the incurable illness. A sympathetic
9 family was perceived as strength, and after the initial shock, the patients began to re-build
10 their lives. They had conflicting thoughts about cancer treatment. The patients felt that they
11 were courageous, but fragile, in the face of their illness. They prepared for the approaching
12 death by discussing the issue with their family members and friends, and planning their own
13 palliative care. The patients expected to be approached holistically. The results of this study
14 are applicable in circumstances in which health care professionals are preparing to approach
15 an incurable cancer patient as an individual, instead of simply as a medical case. The results
16 can also be utilized to develop evidence-based family-oriented palliative nursing for cancer
17 patients and to better identify the expectations and needs of the patients while receiving
18 treatment.

19 Keywords: incurable cancer, coping, support

20 **1 Background**

21 A cancer diagnosis is a life-changing event for patients. A serious illness interrupts the daily
22 lives of patients, arousing anxiety and uncertainty both in them and their loved ones. In
23 nursing, it is vital to bear in mind that patients remain part of their families and communities
24 regardless of their illness.¹⁻³ The World Health Organization (WHO 2017) takes all these

1 issues into account by defining palliative care as the active and holistic treatment of patients
2 with an incurable or life-threatening illness and their loved ones. The objective of such
3 treatment is not only to relieve symptoms but also to guarantee the best possible quality of
4 life. To succeed in this, a partnership between patients, their loved ones and the health care
5 staff is needed.⁴⁻⁶

6 Coping refers to the ability of patients to cope with problems associated with their health
7 status and changes in it.⁷ Coping is regarded as a deliberate and flexible way to control stress,
8 as an active and evolving process. The outcomes of a successful coping process include
9 adaptation to the new situation in life, improvement in the quality of life and the feeling of
10 being in control. In the case of incurable cancer patients, coping is portrayed as an emotion-
11 focused process that is difficult to compare to the coping processes of other people.⁸⁻⁹

12 Health care professionals can alleviate the anxiety and promote the wellbeing of patients by
13 providing support and personalised information. What is crucial, is how palliative care
14 professionals approach patients. Recognising and understanding the patients' situation in life
15 and creating a safe environment are significant for the coping process. A part of this process
16 is developing the therapeutic relationship by reciprocally listening to the patient.¹⁰⁻¹¹ A
17 systematic literature review was conducted before this study to identify factors promoting
18 coping of incurable cancer patients¹². The purpose of this article is to promote the importance
19 of approaching the patient as whole. There is a need to improve family-orientated palliative
20 care nursing. Therefore, we do need to understand the coping manners and needs for support,
21 asked directly from patients.

22 2 Purpose

23 The purpose of this study was to describe the coping processes and support needs of
24 incurable cancer patients. The objective was to produce information that can be utilised to
25 develop evidence-based family-oriented palliative nursing and to recognise the needs and

1 expectations of both patients and their loved ones during the palliative and disease modifying
2 treatment. The research questions were:

- 3 1. How do incurable cancer patients cope with their illness?
- 4 2. What kind of support do incurable cancer patients need to cope?

5 **3 Methods**

6 3.1 Study design

7 The research project was carried out as a qualitative study, and the research data were
8 collected from thematic interviews based on the literature review. The literature review was
9 conducted prior to the study, to examine previous studies and to develop the thematic
10 approach of this study. The themes of the thematic interviews were mulled and developed
11 based on the review. Content analysis was selected as the data analysis method. It proved to
12 be flexible, open and evolved as the research project progressed. ¹³⁻¹⁶

13 3.2 Recruitment and sample description

14 The research data were collected by interviewing patients from the Department of Oncology
15 at the Tampere University Hospital. Nurses at the department approached patients satisfying
16 the inclusion criteria to enquire about their willingness to participate in the survey in August
17 2016. The inclusion criteria were that the patient 1) has been diagnosed with incurable cancer,
18 2) was over 18 years of age, 3) was undergoing disease-controlling chemotherapy or
19 palliative care and 4) was able to understand the nature of the study, participate in the
20 interview and sign a consent form. A bulletin describing the study was drawn up to allow the
21 potential participants to familiarise themselves with the study. The total number of research
22 participants was 16 (n=16), nine of who were women (n=9) and seven of who were men
23 (n=7). The mean age of the participants was 65 years (range 28–86).

1 3.3 Interviews

2 The thematic interview is structured around a specific theme and progresses in accordance
3 with that theme. In this study, the themes were defined relatively loosely to shed light on the
4 diversity of the phenomenon under investigation. The sufficiently quiet and safe nature of the
5 interview setting facilitated genuine interaction with the interviewees. The location of the
6 interviews was selected based on the wishes of the interviewees, either in conjunction with
7 their visit to the hospital or at their home. The mean duration of the interviews was 33
8 minutes. The interviews were recorded and transcribed for analysis.¹⁷

9 3.4 Data analysis

10 The data analysis was conducted by means of inductive content analysis and guided by the
11 purpose and questions of the study. Inductive content analysis was done by two reseachers. At
12 the beginning both researchers analyzed equal parts of data, but categorization phase was
13 done together. In examining the data, attention was paid to factors relevant to the research
14 questions and to similarities arising from the data. The data were reduced to concepts that
15 were categorised to describe the phenomenon. Utterances deemed to describe the
16 phenomenon were utilised as units of analysis. The direct quotations were selected to give a
17 voice to the participants and describe the differences and similarities between the
18 categories.^{13-16, 18-19}

19 3.5 Study reliability

20 The reliability of the study was evaluated at different stages of the research project by
21 utilising the concepts of credibility, confirmability, reflexivity and transferability.¹⁵ The study
22 was conducted in accordance with the principles of good research, carefully and with
23 integrity from the very beginning. The selected method proved appropriate and functional for
24 the study. The research project was recorded in its entirety to allow other researchers to re-
25 trace how the study progressed. Reliability was enhanced further by means of researcher

1 triangulation, for example by using two researchers. Both researchers also kept a research
2 diary and took field notes. The diaries contributed towards the reflexivity of the study by
3 allowing the authors to assess how they may have influenced the data and research project.
4 As phenomena, coping experiences and support needs experiences are transferable to other
5 contexts, and the conclusions drawn from the data were substantiated by other studies.²⁰⁻²¹
6 The data were collected and analysed simultaneously to ensure the degree of data saturation
7 could be documented.¹⁴ The reliability of the research data was enhanced by producing audio
8 recordings of interviews. Audio recording is less disruptive than filming. The quality of the
9 recordings was good. The data were fully transcribed by the researchers, who in doing so
10 could re-live the event and textually re-construct the reality of the interview. Voice of the
11 participants was successfully ingrained in the text by utilising direct quotations.¹⁷

12 3.6 Ethical considerations

13 The study was conducted as a survey and each of its participants was treated as with respect,
14 as an individual. The Regional Ethics Committee of the Tampere University Hospital
15 approved the study (reference number 2016/16069H) and permission to perform the study
16 was received from the Tampere University Hospital. Nurses at the chemotherapy and
17 palliative care outpatient clinics approached patients satisfying the inclusion criteria to
18 enquire about their willingness to participate in the survey. A bulletin describing the study
19 was given to the potential participants to familiarise themselves with the study. The patients
20 who expressed their willingness to participate were required to sign a consent form.

21 The data collected from the interviews were processed confidentially, in compliance with
22 non-disclosure obligations and without disclosing any personally identifiable information to
23 third parties. The names of all people, places and streets were deleted from the data.^{16, 21-23}
24 Incurable cancer patients are a vulnerable group of patients. Participation in the study was
25 therefore voluntary and the participants could withdraw from the study. The researchers

1 remained sensitive for possible negative effects on patients throughout the whole study and
2 comfort of patients was taken care of under the interviews.¹⁶ The researchers had developed
3 an understanding of the nature of palliative care based on their prior work experience and
4 professional expertise.

5 4 Results

6 4.1 The coping of incurable cancer patients

7 4.1.1 The incurable nature of the illness temporarily interrupting life

8 The life of the patients was like a roller-coaster ride at the onset of the incurable illness. The
9 patients felt that *the balance of their life had changed*, although they had been able to
10 mentally prepare for being diagnosed with incurable cancer based on their previous
11 symptoms. Living with the illness was described as a battle.

12 “You’ll just have to live with this thing, there’s no alternative. And yet you may be
13 thinking that... you’ll wait and see if you’ll get rid of this completely...” (Interview 7)

14 The patients regarded continuing the everyday life as increasingly important. The cancer had
15 a limiting impact on their ability to perform household chores, forcing their loved ones to
16 take more responsibility. The patients felt that their *limited ability* had changed their life from
17 that of a healthy to that of a sick person.

18 “Sure, I’ve had to cut back on all of the work that needs to be done. I’ve had to cut
19 back on chopping firewood and all kind of physically tough activities. I just don’t have the energy.”
20 (Interview 14)

21 The patients had had to give up ways of life they had become accustomed to and felt that *the*
22 *scope of their life had become narrower* due to limitations on their social relations. For
23 example, they had had to entirely give up travelling abroad.

24 4.1.2 Interacting with the surrounding world

25 The patients identified their spouse or partner as their most significant supporter. Their
26 relationship had strengthened despite the cancer and the patient and spouse had decided that

1 *the illness will not come in between their relationship*. Family support and the ability to talk
2 about the illness openly were also regarded as important.

3 “Our marriage has only gotten stronger. Because we’ve only got so little time, we’re
4 trying now to live to the fullest. In a way, it’s about us knowing that we don’t have too much time,
5 and so we’re trying to prolong it.” (Interview 9)

6 *A sympathetic family was a resource* and regular contact with family members facilitated the
7 coping process. The patients did not consider it difficult to talk about their illness and felt that
8 humour helped to talk about it. Nevertheless, most the patients only wanted to share their
9 illness with their inner circle. The pity of others did not feel good and, as a result, the patients
10 wanted to *use their discretion in sharing their illness* with others when, for example, leaving
11 the house.

12 “I’ve been open, absolutely open, I haven’t hidden this from anyone. But then again I really
13 don’t want to call too much attention to it (the illness).” (Interview 12)

14 4.1.3 Moving forward after the initial shock

15 Time encouraged the patients *coming to terms with the nature of the illness*. The patients
16 considered it important that their life had direction and purpose. They had to come to terms
17 with the illness, as they had no other option. They also drew attention to the significance of
18 having a positive attitude and living in the moment.

19 “I mean it’s important to have something to aim for. You need to have a direction in
20 life. People have jobs, homes, they make children, get promotions, and everyone has a story like that.
21 Life story becomes fuller as you reach certain milestones. You’re able to write your own life story,
22 which is going somewhere instead of being stuck on the same page all the time.” (Interview 17)

23 The patients could improve their well-being by taking into consideration their own resources
24 and the limitations imposed on their life by their illness. They sought to make the terminal
25 cancer diagnosis their own and, as a result, could *understand the meaning of the incurable*
26 *cancer*. They were grateful for every moment. Firm religious faith provided some of them

1 with strength. Those who were religious, estimated that *spirituality and faith in God* and the
2 religious community had enabled them to deal with the pain and emptiness caused by their
3 illness.

4 “Religion is of course a part of it in the sense that we believe in re-union, after we die.
5 Religion gives you a longer-term perspective, beyond the difficulties. Even though this is what’s real
6 right now, there’s hope... there’s hope of something better.” (Interview 9)

7

8 4.1.4 Re-building life

9 The patients perceived the future as bright and sought to *live despite the incurable cancer*.
10 They had plans to study and work in the future, despite their serious illness. Some of them
11 felt that *modern cancer medication enabled them to lead active life. They found relief in*
12 *activities they enjoyed*. They enjoyed watching television and could briefly discover other
13 worlds by reading. Other key coping methods included exercise and occasional indulgences.
14 The patients also sought to *lead a healthy lifestyle as a complementary cancer treatment*.

15 4.1.5 Conflicting thoughts during the cancer treatment

16 Managing the everyday life was difficult during as *the illness was ever-present during*
17 *regular chemotherapy sessions*. Patients felt that it was important to *lead a more active life*
18 *during extended breaks in treatment*. The symptomless period between the sessions was
19 enjoyable, as it allowed the patients to be more active and offered them the opportunity to
20 engage in activities they enjoyed. The patients were aware of the limited availability of
21 chemotherapy and had, to a certain extent, prepared for a decision to suspend the treatment.
22 However, they also *hoped that the chemotherapy will continue* and that they will even
23 recover.

24 “I thought that it was good thing, that I had just time for me. Without chemo, I got to spend
25 the summer without that treatment... because it always causes symptoms.” (Interview 13)

26

1 4.1.6 Being courageous but fragile in the face of illness

2 The illness *stirred up feelings of dejection and uncertainty* as the patients felt as if they had to
3 wait on the doorstep of life. The feelings of dejection were caused by their confinement to
4 their home. The patients also felt that they can no longer meet the expectations of others
5 regarding advancing in life. Some of the patients felt that learning the prognosis helped them
6 be more optimistic about the future, whereas others felt that *learning the prognosis limited*
7 *the horizon of life* and restricted their own future. For example, some of the patients preferred
8 not to know when their time with the family was coming to an end.

9 “Now it’s like you recognise that you’ve got widespread advanced cancer, and you’ve
10 been able to prepare for the illness following you around like a shadow and you not necessarily ever
11 being able to shake it off.” (Interview 7)

12 The patients voiced their *concerns about how their loved ones will manage* and adapt to life
13 after their death. They reported that they are *preparing for the approaching death* by talking
14 about it with their loved ones and planning their end-of-life care and funeral. The notion of
15 death was no longer scary and life was more precious, as the patients knew that they had only
16 little time left.

17 4.2 The support needs of incurable cancer patients

18 4.2.1 The encouraging effect of loved ones on coping

19 The patients described *the support of friends as a source of strength* during the illness and the
20 safety net formed by their friends as valuable. They reported that talking to a close friend was
21 easy and that they often met their friends face-to-face but also kept in contact by phone and
22 via social media.

23 “I have a strong network of friends, so that’s been a big help. I’m a bit lazy to keep in
24 touch, whereas my friends keep in touch more often. They call me, and nowadays with the Facebook
25 we also keep in touch through it.” (Interview 2)

1 The patients estimated that they were closer than ever with their friends. They also identified
2 a close-knit circle of friends and loved ones as important for *helping for coping with the*
3 *everyday life*.

4 4.2.2 Strengthening the resources of patients

5 The need for *therapeutic discussions* varied at *different stages of the incurable cancer*. The
6 need for supportive discussions was lower when the oncologic treatment was effective but
7 increased in the final stages of the treatment.

8 “But now the thing is that this illness is in a stage that with the medications starting to
9 kick in, it’s positive in the sense that there’s no need for conversation.”(Interview 14)

10 The patients identified *the encouraging climat at the hospital* and the nursing staff as a source
11 of courage and experienced that contacting and discussing unclear questions with the nursing
12 staff was easy. The support of another cancer patient was regarded as the best form of peer
13 support. The peer support meetings organised by the Cancer Society of Finland and the peer
14 support groups on Facebook offered the patients a medium for sharing their thoughts and
15 experiences. *Peer support was perceived to have an empowering effect*.

16 4.2.3 The broad perspective of professionals on issues related to the illness

17 The patients expected to be *approached holistically by the physicians*, have a positive doctor-
18 patient relationship and receive answers to the questions on their mind.

19 “But whenever I come here to see the doctor, I hardly get any answers about my
20 situation. The doctor only asks me how I’m feeling and whether I’ve been feeling well and so on. But
21 there’s somehow a point that you’d expect to get some answers from the doctor... that the doctor has
22 an idea of my current situation.” (Interview 1)

23 The patients felt that their concerns were heard but expressed their hope that the treatment
24 would focus on the person instead of the illness. They felt cared for after seeing a familiar
25 physician and hoped that they always got to see the same physician.

1 “But then the doctor will change again, it’s never necessary the same one. I’ve been
2 thinking that it should be so that you’d get to always see the same doctor, if possible. It’d be better
3 and you wouldn’t have to start from the beginning every time, in a way.” (Interview 7)
4 The patients expected that they *receive the necessary information from professionals*. Any
5 therapeutic decisions should be made collaboratively with the patient and under no
6 circumstances should bad news about the illness be delivered by mail. The patients estimated
7 that information about the cancer treatment should be provided more regularly, as they had to
8 independently look for information about the cancer and issues related to it. The patients
9 insisted on being *as well informed of their own condition and treatment possibilities as*
10 *possible*.

11 4.3 Summary of results

12 The incurable cancer patients described coping by means of the following phenomena: the
13 incurable nature of the illness temporarily interrupting their life, interacting with the
14 surrounding world, moving forward after the initial shock, re-building their life, having
15 conflicting thoughts during the cancer treatment and being courageous but fragile in the face
16 of the illness (Table 1). The support needs of incurable cancer patients encompassed the
17 following phenomena: the encouraging effect of loved ones on coping, strengthening the
18 patients’ own resources and the broader perspective of healthcare professionals on issues
19 related to the illness (Table 2).

20 5 Discussion

21 5.1 The coping processes of incurable cancer patients

22 In this study, the incurable cancer patients demonstrated both uncertainty about their situation
23 and the willingness to fight the illness, which is in line with other studies.²⁴ As in previous
24 studies, one of the most important coping methods for the patients was continuing the daily
25 routines.^{3, 9, 25-26} The patients identified the support of friends and family as a positive,
26 empowering factor, which is in line with the findings of many previous studies.^{9, 12, 25, 27-28} In

1 this study patients estimated that their relationship with their family had become closer
2 because of the illness and the support of their spouse or partner was similarly described as
3 invaluable, as Koffman et al. (2012) and Möllerberg et al. (2017) have also reported. At
4 times, however, talking with loved ones was difficult, as the patients wanted to protect them
5 from bad things.^{2,24, 25, 29} The patients interviewed to this study selected being open about the
6 illness, facing reality, having a sense of humour and a positive attitude to life similarly
7 contributed substantially to the coping process, which is also in line with other studies.^{26,30}
8 Like in this study, also Wise & Marchard (2013) similarly reported that the personal
9 resources of the patients included not only the ability to understand the meaningfulness of
10 life, but also positive relationships and the willingness to live life to the fullest and enjoy
11 every moment despite the illness. As in previous studies like Giuliani et al. (2015), the time
12 perspective transforms with respect to the future in a way that the patients view the everyday
13 life, despite their appreciation for it, as a reminder of the limited time they have left.^{25, 31-32}

14 5.2 The support needs of patients with incurable cancer

15 The patients interviewed for this study estimated that bad news should invariably be
16 delivered face-to-face, not by phone or mail. They hoped that news related to the progression
17 of the illness will be delivered in a frank and honest manner, but not excessively bluntly like
18 Author et al. (2017) have reported.¹² Similarly, like in this study, also a few previous studies
19 suggest that patients have a strong desire to understand their illness and they search for
20 information online and from peer support groups but recognise that not all the information
21 available online is necessarily accurate.^{10,24-25} As the illness progresses, the needs for
22 information and empathy in interactive situations evolves. According to other studies, a
23 gesture of empathy is a sign to the patients that they are cared for and understood.¹¹ Nurses
24 are at key position in monitoring the wellbeing and responding to the needs of the patients.
25 Patients highlighted the importance of relevant information throughout their palliative phase.

1 As implication for nursing practice, there are possibilities to increase patients' wellbeing and
2 satisfy their informational needs. Like Bash et al³³ have reported, there are clinical benefits in
3 using systematic symptom monitoring on patients' human related quality of life. The
4 monitoring can be implemented both face to face and web-based.³⁴ Patients and their loved
5 ones require open access to information about the progression of their illness, together with
6 counselling and emphatic support regarding treatment options.³² As has been stated, patient
7 counselling, discussions and listening are key for enabling cancer patients to maintain their
8 mental balance and cope with the treatment. Patients with knowledge of the treatment process
9 and its details can retain their confidence in the efficacy of the treatment and their feeling of
10 being in control of their life.³⁵ If the need for symptom centred and psychosocial treatment is
11 expected to increase, palliative care should be integrated into the patient's treatment at the
12 earliest possible stage.¹²

13 **6 The limitations and strengths of the study**

14 A bulletin describing the study was distributed to all patients satisfying the inclusion criteria
15 in the recruitment stage until the number of participants was deemed sufficient to prevent the
16 selection bias of data. The fact that understanding the issue under investigation is both time
17 and culture-specific was borne in mind when dealing with previous studies and searching for
18 topic-related sources.^{21,27} In this study phenomena related to coping and receiving support
19 were examined and described from the viewpoint of the participants. The study allowed us to
20 develop concepts for describing these phenomena and examining their interrelations.^{16, 19-20}
21 Previous studies indicate that the benefits of qualitative semi-structured interviews for the
22 participants include reducing their emotional burden and promoting their understanding of
23 their situation. The interviews offer them an opportunity to express themselves and to be
24 heard.³⁶ Interviewing the patients more than once could have augmented the results of the
25 study, as it would have allowed the researchers to become better acquainted with the

1 participants and delve deeper into their experiences in the interviews. To minimise the risk of
 2 errors in translating the direct quotations, the Finnish-English translation was commissioned
 3 from an outside translator.^{20,22}

4 **Conclusions**

5 This study shows the overwhelming interruption of life caused by life-threatening illness, the
 6 conflicting attitude towards therapies, and fragility of the patients suffering from incurable
 7 cancer, but also how they can be courageous, re-build their lives and plans. The importance of
 8 the support achieved from the families is highlighted as well. Health care professionals
 9 should be able to approach these patients holistically and as individuals, while providing
 10 accurate information about the cancer and its treatments. Familiarity about these factors gives
 11 an important background for the improvement of patient and family-centred palliative
 12 nursing. In the future, more studies are needed about the kind of knowledge patients and their
 13 loved ones truly require.

14 **Conflicts of interest and Source of Funding**

15 None declared.

16 **References**

- 17 1. Eriksson K, Isola A, Kyngäs H, et al. *Hoitotiede (Nursing science)*. 4th ed. Helsinki:
 18 SanomaPro; 2012.
- 19 2. Surakka T, Mattila K, Åstedt-Kurki P, Kylmä J, Kaunonen M. *Palliatiivinen hoitotyö*
 20 *parantumattomasti sairas ja hänen perheensä (Palliative nursing; incurably ill patient and*
 21 *his family)*. Helsinki: Fioca; 2015.
- 22 3. Möllerberg M, Sandgren A, Swahnberg K, Benzein E. Familial interaction patterns during
 23 the palliative phase of a family member living with cancer. *J Hosp Palliat Nurs*.
 24 2017;19(1):67-74.
- 25 4. WHO. Palliative care. /www.who.int/cancer/palliative/definition/en/ Web site. Updated
 26 2017. Accessed Jun, 1, 2017.
- 27 5. Twycross RG. *Introducing palliative care*. 4. ed. Abingdon: Radcliffe Medical Press; 2003.
- 28 6. Anttonen M. *Kuoleman vaikeuden lievittäminen kuoleman todellisuuden kohtaavassa ja*
 29 *ohittavassa saattohoidossa. substantiivinen teoria saattohoidosta potilaan, perheenjäsenen ja*
 30 *hoitohenkilökunnan näkökulmasta. (Revealing the hardness of dying by facing and passing*

- 1 *the reality of death. the substantive theory of palliative care from patient´s family member´s*
 2 *and nursing staff´s point of view*). Tampere: Tampere University Press; 2016. (Abstract in
 3 English)
- 4 7. Liljamo P, Kinnunen U, Ensio A. FinCC luokituskokonaisuuden
 5 käyttöopas. [https://www.julkari.fi/bitstream/handle/10024/90804/FinCC-](https://www.julkari.fi/bitstream/handle/10024/90804/FinCC-luokituskokonaisuuden%20opas_korjattu%20liitteen%C3%A4%20olevaa%20SHToL-luokitusta.pdf?sequence=1)
 6 [luokituskokonaisuuden%20opas_korjattu%20liitteen%C3%A4%20olevaa%20SHToL-](https://www.julkari.fi/bitstream/handle/10024/90804/FinCC-luokituskokonaisuuden%20opas_korjattu%20liitteen%C3%A4%20olevaa%20SHToL-luokitusta.pdf?sequence=1)
 7 [luokitusta.pdf?sequence=1](https://www.julkari.fi/bitstream/handle/10024/90804/FinCC-luokituskokonaisuuden%20opas_korjattu%20liitteen%C3%A4%20olevaa%20SHToL-luokitusta.pdf?sequence=1) Web site. Updated 2012. Accessed 1.Jun.2017.
- 8 8. Lazarus RS, Lazarus BN. Coping with aging. New York: Oxford University Press; 2006.
- 9 9. Thomsen TG, Hansen SR, Wagner L. How to be a patient in a palliative life experience? A
 10 qualitative study to enhance knowledge about coping abilities in advanced cancer patients. *J*
 11 *Psychosoc Oncol.* 2011;29(3):254-273.
- 12 10. Nipp RD, El-Jawahri A, Fishbein JN, et al. The relationship between coping strategies,
 13 quality of life, and mood in patients with incurable cancer. . 2016;122(13):2110-2116.
- 14 11. Blackler L. Hope for a miracle: Treatment requests at the end of life. *J Hosp Palliat Nurs.*
 15 2017;19(2):115-119.
- 16 12. Author et al. Parantumatonta syöpää sairastavan potilaan ja hänen läheisensä
 17 selviytyminen palliatiivisen hoidon aikana (coping promoting factors during the time of
 18 palliative care based on cancer patients´ and his closest one´s experiences. - A systematic
 19 review). *Hoitotiede.* 2017; 29(3): 195-206.
- 20 13. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis:
 21 Implications for conducting a qualitative descriptive study. *Nurs Health Sci.* 2013;15(3):398-
 22 405.
- 23 14. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative content
 24 analysis: A focus on trustworthiness. *SAGE Open.* 2014;4(1).
- 25 15. Kylmä J, Juvakka T. *Laadullinen terveystutkimus (Qualitative health research)*. 3.th ed.
 26 Helsinki: Edita; 2014.
- 27 16. Polit DF & Beck CT. *Nursing research: Generating and assessing evidence for nursing*
 28 *practice*. 9. ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2012.
- 29 17. Hirsjärvi S, Hurme H. *Tutkimushaastattelu: Teemahaastattelun teoria ja käytäntö*
 30 *(Research interview: Thematic interviews´ theory and practice)*. Helsinki: Gaudeamus
 31 Helsinki University Press; 2008.
- 32 18. Alasuutari P. *Laadullinen tutkimus 2.0 (qualitative research 2.0)*. 4.th ed. Tampere:
 33 Vastapaino; 2011.
- 34 19. Flick U. *An introduction to qualitative research*. 5th ed. London: Sage; 2014:587.
- 35 20. Lincoln Y, Guba E. *Naturalistic inquiry*. Beverly Hills: Sage; 1985.

- 1 21. Parahoo K. *Nursing research principles, process and issues*. 3rd ed. UK: Palgrave
2 macmillan; 2014.
- 3 22. Johnson M, Long T. Research ethics. In: Cormack DFS, Gerrish K, Lacey A, eds. *The*
4 *research process in nursing*. 6. ed. Chichester: Wiley-Blackwell; cop. 2013:27-35.
- 5 23. Ronkainen S, Pehkonen L, Lindblom-Ylänne S, Paavilainen E. *Tutkimuksen voimasanat*
6 *(Keywords of research)*. 1.-2. p. ed. Helsinki: Sanoma Pro; 2013.
- 7 24. Sterba KR, Zapka J, Gore EI, et al. Exploring dimensions of coping in advanced
8 colorectal cancer: Implications for patient-centered care. *J Psychosoc Oncol*. 2013;31(5):517-
9 539.
- 10 25. Lobb EA, Lacey J, Kearsley J, Liauw W, White L, Hosie A. Living with advanced cancer
11 and an uncertain disease trajectory: An emerging patient population in palliative care? *BMJ*
12 *Support Palliat Care*. 2015;5(4):352-357.
- 13 26. Mosher CE, Ott MA, Hanna N, Jalal SI, Champion VL. Coping with physical and
14 psychological symptoms: A qualitative study of advanced lung cancer patients and their
15 family caregivers. *Support Care Cancer*. 2015;23(7):2053-2060.
- 16 27. Epiphaniou E, Hamilton D, Bridger S, et al. Adjusting to the caregiving role: The
17 importance of coping and support. *Int J Palliat Nurs*. 2012;18(11):541-545.
- 18 28. Koffman J, Morgan M, Edmonds P, Speck P, Higginson IJ. 'The greatest thing in the
19 world is the family': The meaning of social support among black caribbean and white british
20 patients living with advanced cancer. *Psycho-oncology*. 2012;21(4):400-408.
- 21 29. Bentur N, Stark DY, Resnizky S, Symon Z. Coping strategies for existential and spiritual
22 suffering in Israeli patients with advanced cancer. *Isr J Health Policy Res*. 2014;3:21.
- 23 30. Wise M, Marchard L, Marchand L. Living fully in the shadow of mortal time:
24 Psychosocial assets in advanced cancer. *J Palliat Care*. 2013;29(2):76-82.
- 25 31. Giuliani L, Piredda M, Ghilardi G, Marinis MGD. Patients' perception of time in
26 palliative care A metasynthesis of qualitative studies. *J Hosp Palliat Nurs*. 2015;17(5):413-
27 426.
- 28 32. Bahti T. Coping issues among people living with advanced cancer. *Semin Oncol Nurs*.
29 2010;26(3):175-182.
- 30 33. Bash E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, Rogak L, Bennett AV,
31 Dueck AC, Atkinson TM, Chou JF, Dulko D, Sit L, Barz A, Novotny P, Fruscione M, Sloan
32 JA, Schrag D. Symptom monitoring with patient-reported outcomes during routine cancer
33 treatment: A randomized control trial. *J Clin Oncol*. 2016;34(6):557-565.
- 34 34. Bash E, Deal AM, Dueck AC, Bennett AV, Atkinson TM, Scher HI, Kris MG, Hudis CA,
35 Sabbatini P, Dulko D, Rogak L, Barz A, Schrag D. Overall survival results of a trial assessing
36 patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA*.
37 2017;318(2):197-198.

- 1 35. Fujinami R, Otis-Green S, Klein L, Sidhu R, Ferrell B. Quality of life of family
2 caregivers and challenges faced in caring for patients with lung cancer. *Clin J Oncol Nurs*.
3 2012;16(6):210-220.
- 4 36. Coombs M, Parker R, DeVries K. Can qualitative interviews have benefits for
5 participants in end-of-life care research? *Europ J Palliat care*. 2016;23(5):227-231.
- 6

1 *Table 1. The coping of incurable cancer patients*

CATEGORY	SUB-CATEGORY
THE INCURABLE NATURE OF THE ILLNESS TEMPORARILY INTERRUPTING LIFE	<i>The balance of life changes</i>
	<i>Limited ability</i>
	<i>The scope of life becomes narrower</i>
INTERACTING WITH THE SURROUNDING WORLD	<i>The illness will not come in between relationships</i>
	<i>Sympathetic family as a resource</i>
	<i>Using discretion in sharing the illness</i>
MOVING FORWARD AFTER THE INITIAL SHOCK	<i>Coming to terms with the nature of the illness</i>
	<i>Understanding the meaning of the incurable cancer</i>
	<i>Spirituality and faith in God</i>
RE-BUILDING LIFE	<i>Living despite the illness</i>
	<i>Modern cancer medications enabling patients to lead active lives</i>
	<i>Finding relief in enjoyable activities</i>
	<i>Leading a healthy lifestyle as a complementary cancer treatment</i>
HAVING CONFLICTING THOUGHTS DURING THE CANCER TREATMENT	<i>The illness being ever-present during regular chemotherapy sessions</i>
	<i>Leading a more active life during extended breaks in treatment</i>
	<i>Hoping that the chemotherapy will continue</i>
BEING COURAGEOUS BUT FRAGILE IN THE FACE OF THE ILLNESS	<i>Feelings of uncertainty stirred up by the illness</i>
	<i>Feelings of dejection caused by the illness</i>
	<i>Learning the prognosis limiting the horizon of life</i>
	<i>Being concerned about how loved ones will manage</i>
	<i>Preparing for the approaching death</i>

1 *Table 2. The support needs of incurable cancer patients*

CATEGORY	SUB-CATEGORY
THE ENCOURAGING EFFECT OF LOVED ONES ON COPING	<i>Support of friends as a source of strength</i> <i>Help for coping with the everyday life</i>
STRENGTHENING PATIENT RESOURCES	<i>Therapeutic discussions at different stages of the incurable cancer</i> <i>Encouraging climate at the hospital</i> <i>The empowering effect of peer support</i>
THE BROAD PERSPECTIVES OF PROFESSIONALS ON ISSUES RELATED TO THE ILLNESS OF CANCER PATIENTS	<i>Being approached holistically by physicians</i> <i>Receiving the necessary information from professionals</i> <i>Having knowledge of the condition</i> <i>Having knowledge of the treatment possibilities</i>