

AUTONOMY AND EMPOWERMENT
OF HOSPITALIZED OLDER PEOPLE

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Ph.D.

Volume 2 of 2

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APPENDICES

APPENDIX 1

PATIENTS' SAMPLING PROCESS

Round 1 - 26/09/2006								Gender		Rank of age		
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge plan < 48h	Poor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1		X										
2			X									
3		X										
4		X										
5				X								
6						25	Yes – P4		1		80	
7						25	Yes – P3	1			80	
8						29	No					
9			X									
10	X											
11		X										
12						28	Yes – P1		1	67		
13						28	Yes – P2		1		75	
14	X											
15					X							

Round 2 – 10/10/2006								Gender		Rank of age		
Bed Number	Empty bed	<65 years	≤48h of hospital stay	Discharge plan < 48h	Poor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1					X							
2	X											
3		X										
4		X										
5		X										
6				X								
7				X								
8						26	Yes – P5	1		68		
9						28	No					
10			X									
11			X									
12						20						
13						23						
14	X											
15	X											

Round 3 - 24/10/2006								Gender		Rank of age		
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge plan < 48h	Poor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1						15						
2		X										
3						18						
4						27	Yes_P9	1		69		
5	X											
6		X										
7						18						
8						26	Yes_P7	1		73		
9					X							
10	X											
11			X									
12						28	Yes_P8	1		68		
13				X								
14						30	Yes_P6	1			75	
15			X									

Round 4 - 14/11/2006								Gender		Rank of age		
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge plan < 48h	Poor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1					X							
2		X										
3	X											
4						24	Yes_P10		1	74		
5		X										
6		X										
7						11						
8			X									
9	X											
10						18						
11						12						
12						28	Yes_P11	1		71		
13	X											
14	X											
15		X										

Round 5 – 13/12/2007								Gender		Rank of age		
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge plan < 48h	InPoor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1						30	Yes_P13		1	71		
2						29	Yes_P12	1			75	
3			X									
4						30	Yes_P14	1			79	
5				X								
6		X										
7					X							
8		X										
9	X											
10			X									
11					X							
12	x											
13		X										
14	X											
15					X							

Round 6 – 09/01/2007								Gender		Rank of age		
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge plan < 48h	Poor clinical condition	MMS	Informed consent	Male	Female	65-74	75-84	>84
1	X											
2						24	Yes_P15	1				90
3		X										
4		X										
5			X									
6		X										
7						24	Yes_P16		1		77	
8					X							
9					X							
10				X								
11		X										
12	X											
13	X											
14			X									
15	X											

APPENDIX 2

TRANSLATION OF THE ORAL RECITAL VERBATIM OF NURSE 9

Oral Recital Verbatim of Nurse 9¹

My name is N9. I'm 37 years old, I'm married and I have 2 kids. The oldest is J with seven years old and the younger is R with three years old. I'm a nurse since 1993. I live to my family and I remember my childhood as well. I have memories from when I was 2 or 3 years old. I remember very well when my brother was also a kid... and the games we used to play... and I also remember my grandfathers and the relationship I had with them, both from my mother's and from my father's side.

I had a more close relationship with my grandparents from my father's side. But I also remember very well my grandparents... from my mother's side... grandma was a very strong character... she had authority over their children... she had 17 children. Grandpa was cute... very thin, tall, completely bold... he had a little box where he kept tobacco... he used to make his own cigarettes... he was a wise man. He travelled a lot to Brasil. My mother was the younger daughter... when she was born my grandmother was nearly 50 years old. As my grandmother was quite old and my grandfather was always travelling, she grew up in a boarding school. My mother didn't like it at all. Even in photos... she had a face of a blond angel but an expression of anger. She missed her parents... even though she also learned to be independent...

I have a closer connection to my father's side of the family... I often stayed with them when my parents were working. I was the oldest grand-daughter and the favourite as well... she is over 80 years old... I was a happy child. They lived in the north of the country and I also lived there for a while. When I returned to Lisbon I always went back to visit them and stayed for two or three months. Then they had some discussion with my uncles and broke relationships. They don't talk to each others. I stopped going there as I didn't like that situation.

¹ Rather than looking for the most correct English form, the translation tries to stay as close as possible as the Portuguese text (which often is not gramatically correct).

My grandfather died sometime ago. I loved him. But I do remember when he was alive...Some time ago, an old uncle (my father's uncle) was ill and his sons and daughters were already preparing his burial... and then my parents brought him to his home town, to the hospital and he was treated and did recover. But the look in his eyes did change... After that, well... he quitted... he had 6 strokes, and deteriorated a lot... and finally passed away... Once in a while I helped my mother to take care of him... and I'll always remember the look of good-bye in his eyes...

My grandfather died when I was pregnant... I already visited his town several times but I never had the courage to go to the cemetery... I don't know... I don't like it... My grandmother lives there and I don't visit her very often... sometimes I think I should at least call her... at anytime she might be dying and... I'll regret not to have spent some more time with her.

[Silence]

The way I see the world changed significantly after my son's birth. I was working in a ward where many people died, everybody call it the Tarrafal²... people usually say that after the first patient death... [Pause]³ but no... Often people touch us in a manner that make us think... [Pause] And I am a kind of person that loves to talk about these things... but often I'm afraid to look sentimental... and I used to think that people should never die alone... and that is difficult to me... when we are young nurses we do not stop to think about things...

For example... the patient stops⁴ ... we do CPR and we move on... we do not think in the action in itself... but after a while... I think that we start thinking over it... For example I had a patient she had a heart problem... she was really dying... and they⁵ even performed an angiography... and she should stay still in supine position... but she was not comfortable... she wanted to be turned laterally...she

² The name of a political prison where people were tortured and often died, in dictatorial period.

³ The inflection, pause and tone suggest an interpretation like 'things change'.

⁴ It means cardiac arrest.

⁵ Presumably the doctors.

had already had morphine... but she couldn't sleep... she wanted to move a little... what difference would it make one more haematoma? If I turned her to lateral decubitus the back pain would be relieved...And I told him⁶... I deeply regret that on that moment I turned my back and left... to avoid interfering with his work... On the other day I knew that she was dying... but they even placed a pace-maker. I may understand their point of view but it was unnecessary pain.

Once I was with an old lady – she had a severe condition and she knew she was dying – I was taking care of her and she asked me to take off all that stuff... it was unbearable to her. And she stated clearly that she didn't want CPR... and doctors were aware of it [Silence] and in the meanwhile she stopped... and everybody knew that there wasn't any possibility of survival, and she also was very aware of that... and in the meanwhile she stopped and the doctors came immediately and started CPR... it's something... it looks that it is automatic... mechanical... and I even argued with the doctor: 'But doctor she didn't want to have CPR' ... but we kept for over one hour with more this and that... needles here and there and everywhere... I felt revolted, shocked... We all knew and we all complied...why couldn't she have died peacefully?

[Silence]

Sometimes we do not even give family the opportunity to be with older patients... I had a patient that her condition was deteriorating and the son wanted to be with her... and she was dying. They⁷ took her to put a pace-maker and she died... it was quite a discussion in my department because in addition the son was a physician in my hospital and nobody told him. Family at least should have the sufficient information... in order to allow them... to be there in the last moments, close to their relatives...I question myself a lot about it... family should have the opportunity... If they knew it was close... And sometimes they do... And I often ask myself... Don't I have anything to say to the patient? Don't I? May be the patient doesn't put it into words but he knows that he's going to die... Doesn't he

⁶ Presumably, the doctor.

⁷ Ibidem

have the right to know it? Would he like to speak to someone... or to leave a message? May be that for too many colleagues it doesn't make sense but it does to me. They may want to have the possibility to sort out any unsolved issue... may be they are not aware that death is so close...

[Silence]

Well... that's it... I'm done. I believe I always gave much attention to older people. I believe that nurses may be the family patients do not have, whenever they are alone and tied to a bed... and they say they have heat, but when we touch their hands... they are cold. They need someone to touch them, to give them attention... someone who gives them a bit of attention; someone that gives them some affection... the true is that my relationship with older people taught me a lot... May be even to face life differently and to be less worried about death.

[End of recording]

APPENDIX 3

TRANSLATION OF THE WRITTEN NARRATIVE OF NURSE 14

Written narrative of Nurse 14⁸

Lessons elderly people taught me.

In my written narrative I am going to tell stories which taught me something about autonomy and empowerment of elderly people.

My aunt Mary, my grandmother's sister, she was a single old lady, with seventy six years old who dedicated her entire life to her family. She was sweet, very handy and with an incredible inner strength. She always had a solution for everything, she always had a word to everyone, but as she said, she had hypochondria. But in spite of all her complains she always managed to overcome her problems.

On March 2004 she started to have abdominal complaints. A few days later a colon cancer was diagnosed. She underwent surgery. She overcame the situation keeping hope but she never mentioned the disease's name. She stayed at the hospital only the minimum necessary days to recover and she was always cared with love and affection.

But it was a galloping disease and in two-month time she was quite impaired and dependent. Her silence regarding disease was always respected. We tried to show her our love through all our gestures. We felt she was living the last days of her life quite peacefully. Regardless her increasing dependency we always valued her opinion and her feelings, preserving her self-determination and dignity. This kind of attitude did also tranquilize us. And I say "us" because all family acted consonantly on care, affection and love. To me it was a particularly painful experience. Firstly because it was the first experience of death of someone so close, and then because I followed her always until the end. I often felt powerless... I wished I could do something else. Whenever decisions were needed all family turned to me... as I was the nurse. Whenever I cried (and I often did it)

⁸ Rather than looking for the most correct English form, the translation tries to stay as close as possible as the Portuguese text (which often is not gramatically correct).

everything fell down. Everybody thought that I should be strong as I was daily in touch with disease and death. My aunt passed away in June 2004. We were at her side until the end. She never showed bitterness or anger. Despite all suffering, the look in her eyes was always tender and thankful. She cared for us, and, in that moment, we all cared for her providing comfort, dignity and love.

My grandfather was a farmer with 87 years old that for the first time in his life was ill and hospitalized. He used to deal with life in a very simple way. He lived all those years in his isolated cottage in the mountain. He was on holidays with us, got sick and stayed with us. Suddenly he was out of his environment, hospitalized for the first time. A colorectal cancer was diagnosed. He became depressed... expressing an immense sadness. He started to isolate himself and he was always talking about death. Owing to his depressive mood, family did not want to reveal diagnosis to him. The MD agreed. A surgery was proposed to him but firstly he refused. Later on he asked his children for advice and he accepted to have surgery and he stayed at hospital longer than expected.

It was a very difficult time for him. Firstly because they took him the false teeth... but also due to his pronunciation nurses did not understand him... they labeled him as confused, and they gave him sedatives... We started to find weird that he was in such apathy, and so sleepy. Our family talked to health team and the problem was sorted out. But I understood that he felt threatened in his dignity, in his freedom and in his will. He used to say to me: «My dear, why do I have to bath every day? They take all my clothes, and let me naked just covered with a bed sheet... than it's a rush to shower and they rub me as I was too dirty. They give me orders and they do not listen what I have to say. They don't even look at me». I tried to mitigate some issues saying that the ward was full and that staff was short for so many patients

He was bedridden on the first days. On the following days he could transfer to a chair but he could not walk alone due to the infusion and bladder catheterization. He began to look depressed, he stopped walking, and didn't feed himself

anymore... and got even more depressed...He was sad and so was I. He left hospital dependent and impaired. However at home he unbelievably recovered in two weeks. When we went home he decided what he wanted to eat. He did a huge effort to eat properly as he was never hungry. He refused to go to physiotherapy and started exercising at home, all by him. And he did recover. His joy was also my joy. He told us jokes, we used to laugh. He wanted to go to church, to the holy mess. I realized that in hospital my grandfather lost the capacity to do certain things however the worst thing was the fact that he felt his freedom and his will threatened. At home his feelings and his will were understood and welcome. He overcame that difficult period and he had a huge smile when he was able to return to his home. Today I do understand that when he recovered the power to rule his life he also succeeded to recover physically.

Next story is about Mrs. Aida. She has a COPD and she is one of our regular patients due to her dyspnoea crisis. Once she developed acute pulmonary oedema and she had to be admitted in our ward. When I started my shift my colleagues informed me that she had had a very difficult night and that due to confusion and some agitation she was sedated and with restraints.

Seeing her tied to the bed was a shocking image as this woman was always very independent and gay, well dressed with vivid colours and wearing her make-up. Now she was dishevelled in a white gown and a sad expression. It didn't look the same person. I gently approached her and started to talk to her. She started to recognize me and to remember that she had a sever crisis on the eve but she didn't remember the night or why she had those 'bracelets' on her wrists. I tenderly explained that she was confused during the night and asked her to try to remember why. She suddenly remembered that she was having psychiatric medication and that in hospital she was not taking it. I looked for the MD and explained the situation in order to update the prescription. It was good to see her recovery and the renewed proud on self-care. To be well dressed, with the hair done, to put her daily cream were important things to her self-esteem. Hopefully this incident did not have a very negative effect.

I remember an older man who was discharged from ER but nobody came to take him home. It became a social issue. Most part of times these situations are sorted out in two or three days or at least in a week. But this man happened to stay with us for two months. He had a very sad facial expression, he hardly smiled. He almost didn't speak and the most part of time he was hiding his head under the bed sheet. It seemed that everything he did was mechanical... without any kind of emotion. He refused any attempt to dialogue. Today... when I think on this situation I realize that the time he was in hospital must have been particularly difficult. Firstly due to family abandon, than by loneliness and rejection, by the inability to care for him and also by the dependence on others. Realizing that this ER department would be his home for that period... surely he must have felt very uncomfortable.

When I think over situations like these, related to autonomy and empowerment, I consider that we (the health team) could be much more effective. Most part of time we do not ask for patients' opinion, we undervalue their feelings and we do not give opportunities to make choices, even on basic issues like food or clothes. Our excuse is always lack of time and lack of nurses.

In this case, and just talking about me, I think I failed. Realizing what autonomy really means I feel that I could have done much better towards his physical and psychological well being.

APPENDIX 4

TRANSLATION OF THE DIARY OF NURSE 11

Diary notes of Nurse 11⁹

I - Something that made me think today?

Today is my second day of classes; I have some expectation about the way the course will be developed. I started to think how I will be able to mach family, work and study along this year. It was hard to get focused after a working day, about the tasks I did and about things I asked others to do. It is a new experience, to come back to school, as a worker and a student. It is a challenge that I will try to overcome in a positive way, and keeping mental and physical health. I hope this experience will enrich me both at personal and professional levels. And I hope to learn useful things to my daily practice which I hope to use in practice.

II - What did I learn today?

Today I learned about competence concepts and about the different proficiency levels that we may have. It was interesting. I was able to stop and think for a while about the ways to assess practice and our performance as nurses. We also had a debate about lived experiences and how our experiences influence our daily practice in each one's contexts. It was really interesting. It helped me to think about my own practice and to understand in what level I'm performing. The way we discussed it related to our own experiences was very interesting. Through my experiences I think I assess myself between competent and proficient levels. This is a very adequate discussion to our profession.

III - In the past weeks I have been often thinking about situations I lived in my daily practice. Nearly 5 years ago I had a CKD patient in terminal stage. He came again and again to my department, staying a few days to do some palliative therapy. I had a really an empathic relationship with him. It was a difficult situation as he shared his fears and all his anxiety, particularly when I was present. I let her wife being there with him most part of time, to help and support him. At

⁹ Rather than looking for the most correct English form, the translation tries to stay as close as possible as the Portuguese text (which often is not gramatically correct), including text format.

each time he came he asked for me and he wanted me to care for him. He always asked if I was on duty and if so he always asked that he wanted to be cared by myself. I realized that he trusted on my competency but also he relied on my support and attention. I thought I wasn't doing anything special, but, after all, I was. He acknowledged me as 'his nurse' and he trusted on me.

IV - The writing experience

I realized that writing is important to develop reflexive knowledge towards a professional and helping relationship. Did I act in the right way? Did I have a correct attitude? How today experience will influence my future behavior?

V - According to my professional experience, to be old is...

...To be over 75 years old. To be old is to have a background that gives wisdom but without having the enough energy to accomplish life projects. It's having lots of disabling diseases. It is to needing permanently someone to help us. It is to have experience. It is to need someone's arm to make the final journey.

VI - If I wrote my life story in a book or in a film the title would be 'Starting from ground zero'.

VII - Autonomy at a glance

In a first thought, without going to the book, autonomy means to me doing things without help, having one's initiative, knowledge, and also taking the risks. It is to have decision power and to know how to preserve one's attitude or behavior, with logical arguments.

VIII - I awaked for the meaning of two different concepts in the field of geriatric care which semantics I completely ignored: autonomy and empowerment. When I listened to our teacher's narrative I suddenly became aware how wrongly I took autonomy and empowerment on older people. I realized how many times I forgot that older people are free to make their own decisions. I realized the relevancy of autonomy and its relation to empowerment, autonomy and independence and that

I need to enable people to be self-directed, to preserve their citizenship rights and to give them the freedom to choose.

IX - Listening to my recorded stories

To listen to my own voice was weird. It seemed another person. When I started to write I added some more issues and details. In the audio record I just told the stories that came into my memory at that moment. About autonomy and empowerment I learned that it is the freedom, the skills and the willing to manage one's life, to exercise one's rights, as citizens. It was a learning experience that enriched me with reflection on practice.

APPENDIX 5

TRANSLATION OF THE INTERVIEW VERBATIM OF NURSE 2

Interview verbatim of Nurse 2¹⁰

[Interviewer] In the first place I would like to thank you for accepting do discuss this issues related to your experiences... related to nursing care of older people, to autonomy and empowerment... and related to the experience of biographic work. And the first thing I would like to ask you was... following this biographic experience what are the meaning of autonomy and empowerment to you, in the context of geriatric care?

[N2] Well autonomy I consider to be a more independent person, a more autonomous person, able to make their own decisions. And empowerment may what we demand from people... for them to make decisions, whenever they are not so autonomous... I think that's it! [Silence]

[Interviewer] You mean that this what you learn through biographic work?

[N2] I learned a lot... a lot... particularly, particularly... Particularly listening to others, thus... biographic work... biographic work was a different experience, something I was not used to... we put in perspective our lived experiences with older people... an issue quite delicate to me... At the beginning I felt apprehensive... about telling my stories... even into the small group, about showing my feelings in front of people I hardly knew. However, that initial feeling wasn't an obstacle... It was interesting to listen to other people's stories, obviously different from mine, but strangely having the same kind of feelings. I consider really important to reflect over my life trail with older people, and to acknowledge that all those lived situations influenced the way I am, my way of being in life, and in nursing. Following this experience I became aware of my feelings and handicaps, and I think I provide better care now for others who also have a life story full of beliefs, hopes, values, experiences which also influence their health/illness process...

¹⁰ Rather than looking for the most correct English form, the translation tries to stay as close as possible as the Portuguese text (which often is not gramatically correct).

[Interviewer] So you think that autonomy is related to...

[N2] To each one's particular life, to his experiences, to his way of being in life...

[Interviewer] And in your life, in our experience, in your own way of being a nurse the meaning is...

[N2] Well... to me it was always important to listen to the other person, it was very important... the human side is vital... not only the technical detail, to place an infusion, to place a catheter... human relation is the most important thing... the relation with the other person that allows him to own oneself... For example, this week, I was not expecting at all, but I received a flattering remark, one of my patients thanked me because I succeeded to make his wife more independent...

[Interviewer] Could you tell me what happened?

[N2] Well, she was diabetic... and she was depressed. And this week I have always been on the day shift, and she managed to drink her milk by her hand, and to talk, and to transfer from bed to the chair... all things she was not able to do before...

[Interviewer] Why not?

[N2] Well, all because nobody listened to her... may be to stop and listen... is important... to give people time to do things at their rhythm... to give opportunities... on daily life we do not stop to think why we do not give patients the choice to choose...

[Interviewer] So according to you experience in hospital older people loose autonomy?

[N2] Yes... in hospital there are no favourable conditions... let's say... the autonomy and the power... there is no time... time to listen to the other person due to an excessive workload... and I think that having the time is crucial to elderly patients... by the way, we¹¹ are doing a research project, and one of the questions

¹¹ Meaning the nurses in her department.

we are asking the patients is “what is a nurse to you?”. And they usually say that it is more than giving the pills... it is to being to listen, in order to allow patients to express feelings, fears, and that often nurses do not have time... but besides the lack of some nurses... we... we do not want to spent a little time with them.

[Interviewer] So you are saying that beyond the workload...

[N2] Nurses do not, do not want, no... No... And with older people this is very important... may be the most important thing... and if we do not give people the time to talk, we are cutting down their autonomy.

[Interviewer] So listening to older people is fundamental to autonomy?

[N2] Absolutely.

[Interviewer] And how could nurses change it?

[N2] Look... in first place we should start thinking that one day we will be older too... because we will... and we would like that time were given to be listened... one day we will be older too... [Silence]

[Interviewer] Right... and what else could be done now, for example in your department?

[N2] Well... perhaps I should promote the discussion in the team... if we could share our experiences, like we have been doing here in the school... and why not to invite patients to this discussion? But it is not usual to give patients' a voice...

[Interviewer] Why not?

[N2] Because we do not allow them... maybe sometimes they want that freedom but we do not give the necessary freedom... we cut that freedom...

[Interviewer] Why do we do it?

[N2] Either because we do not have time, or because we do not have someone to help us to care for patients... Sometime people would like to have a moisturiser to feel better, to have the hair done...

[Interviewer] And regarding decision making?

[N2] Well... often is the MD who arrives and says... this patient must get up from bed, and often the patient does not want, does not want to get up, and I try to sort it out, and listening to patients to do what they want... [Silence]

[Interviewer] And what do patients want?

[N2] They want to be listened... they love to be listened... they love to tell stories and they love to be listened... it is very important to older people... that's it!

[Interviewer] Right! In your written narrative you talk about a situation that strongly shocked you... were the nurse was quite abusive... would you like to explore it?

[N2] Yes... I was a student... and an old patient was near the floor-stairs and the nurse wanted her to go to the ward but this lady didn't want to... and the nurse wanted to oblige her to go... and as she didn't move the nurse pulled her hair... it was terrible... I do not know how to explain... I was a student, I couldn't do anything... It was a trauma to me... this lack of humanity... it was absolutely violent and it was not necessary... why couldn't she go later? She was a psychiatric patient... and it was absolutely inappropriate... and in the daily meeting we discussed it but we couldn't do much... we were just students... we didn't have much voice. I never saw anything so terrible!

[Interviewer] Humm! Further on, in your narrative, you talk about respecting older people's decisions... would you like to explore it?

[N2] Well... yes! I talked about my grandmother... For example at a certain moment she wanted to go to a nursing home, we were not very happy about it... but it was her choice... she was there but she travelled, and she made new friends... but regarding my husband's grandmother the situation was different... she developed Alzheimer... it was impossible after a certain moment... she couldn't be left alone... and we found a nursing home near our house, we visited

her daily... we cared for her, for the hair, for her image... I think family is very important... to keep autonomy.

[Interviewer] And in hospital?

[N2] Yes... yes it is possible! I use to do it. I usually ask families to bring personal belongings, the things patient would like to use... There are people... nurses who don't like it... they remove all patient's clothes and now put them in a hospital vest... now, because some years ago people could be naked under the bed sheet...I like to do it but some people don't ... And it is not a regular practice of every nurse.. only a few value this kind of gestures... to value older people's self-image and to integrate family in care... only a few nurses do it... only a few give patients and family some power...

[Interviewer] Why? Is it difficult to include family?

[N2] No, it is not very difficult to give people that power...but some nurses don't like it. [Silence] Some people have this kind of patience but others do not... And patients would benefit, they would be more autonomous even if they are dependent... maybe less people would say "I wish I could die!" ... probably they wouldn't say it so often if we gave them some more autonomy...

[Interviewer] Why do you think people say they would like to die...?

[N2] Because they feel lonely, very lonely... Particularly in Christmas, in New Year... family dump older people in hospital... it is like a storehouse... And when older people feel dumped by family they quit ... I often visit hospital in Christmas to bring some sweet things to the patients, and to give a little attention... particularly to those who do not have family...

[Interviewer] So you mean family is important to keep autonomy!?! And that nurses should integrate family in care, is it?

[N2] Yes! Absolutely!

[Interviewer] You also mentioned in your narrative that you lived the situation of being a family carer of a hospitalized older woman... would you like to analyse it?

[N2] Well... it was my mother... She was in coma. Nurses had a good behaviour... a great behaviour. They let us always stay with my mother, my sister came from Germany, because they told us she didn't have big chances to survive... and all the time that my sister was here she cared for her, they let her in... and let it be her to give her bath... she was there in the morning and I was in the afternoon after my shift... I think that because of this my mother succeeded to get out from coma... she was in a severe hiponatremia... and they were saying all the time that she wouldn't make it. But I'm sure that from bathing, to massage, to communication... all of this was very important and nurses let us always be there and this is very important to patients in a coma or at the end of live...

[Interviewer] Did you talk about it with your mother?

[N2] No I didn't... I didn't have the courage... But I felt she was really proud of her daughters. **[Silence. Some tears drop.]**

[Interviewer] Would you like to stop, or to add anything else?

[N2] Well... I wish I could help more. And I hope that the biographic experience will help others to grow as it helped me... I think that if we did this in our contexts, reflecting on our own experience and learning on it... it would change nurses' attitudes and behaviours and would improve nursing care, because we became aware of our actions, of what we say and what we do. We learn to listen to others, we develop respect for other people's stories, we discover that the person in front of us is so respectable as we are... if we could only meet once a month to reflect, to share experiences... to grow both as nurses and as human beings...I loved to have the biographic experience... it was one of the best experiences I had. I would like to let you a thought I read somewhere: 'Inside each one of us there are secrets, inner landscapes with plains and valleys of silence and secret paradises.'

[Interviewer] Thank you.

APPENDIX 6

TRANSLATION OF THE INTERVIEW VERBATIM OF PATIENT 8

Patient 8 – Interview 1¹²

[Interviewer] We heard a lot about older people's autonomy and I would like to ask you what does it mean to you... in your life, to be autonomous?

[P8] Well, autonomy of older people, I think that older people do not have any autonomy. In the extent we're ageing we lose... we must submit to more and more social issues... some of them deleterious...

[Interviewer] Could you explain it?

[P8] Let's say..., to travel, to go from one place to another... we do not have the means to do it properly... for example... we do not have money for transportation, we should be entitled to travel with a special pass... if public transports allow older people to travel for free ... I'm not talking about me because I think that I'm over the average, but... well... most part of people do not have a car, they want, they want to go and they do not have it... or bus, for example, they do not afford to buy the tickets... I think that older people's autonomy includes having enough money... for example, money for transportation... we want to go anywhere how may we go? We do not have money... retirement is short¹³. I think we should have a card to travel for free... the company would not go to bankruptcy...

[Interviewer] So you mean that financial constraints are important?

[P8] Yes... Unfortunately, in our country this is not a reality... They should make a statistic of how many people travel each day in public buses... Another issue is in public services reception: as they see us it's immediately «here comes the pain in the ass! » Attendants do not have the due education, they neglected good manners... formerly elders were respected... This is not a political issue... moreover I'm not a political man... well, I can't say that because really nobody is out of politics... But I'm not affiliated in any political party... But I consider that

¹² Rather than looking for the most correct English form, the translation tries to stay as close as possible as the Portuguese text (which often is not grammatically correct).

¹³ The minimum retirement pay is nearly 250€ per month.

with the disappearing of a certain social class... mid class... and the raising of a certain social class that was not prepared to go up, some things were forgotten... education, good manners... particularly towards older people. I remember in my father's village, older people were respected... it doesn't mean that everyone abided by their will but listened to their advice... nobody dared to turn their back... Not as we hear now... «Here comes the oldie! » I'm not complaining, it is not directly to me... I do not have such problem...

[Interviewer] You are talking about whom?

[P8] Society! I see creepy things, even in television... only new is good... new people, new things, new technology... old stuff is trash... Whatever we say, our experience... it doesn't matter... It's old and it's rubbish! But we do things, and we know things... And I do remember that when I had my work, in the Navy... Now I'm retired but when I was there sometimes I went to sort out something... I was a technician in the Navy... I went and saw that they were doing things that were done four or five years ago were done in a certain way... and had good results, but as it were done by the oldies it was to forget, to trash... It doesn't matter... it is to forget because now only new is good. Old is trash... but this trash is knowledge... Formerly we did not have social security we had to work... I saw many things, I learn many things... And nowadays these people do nothing for society... and we are trash... I was in the war, I saw people dying... families in the most absolute misery... who will pay for it? They gave their lives and receive nothing...

[Interviewer] Are you saying that society undervalues older people who dedicated their entire lives working to the country?

[P8] Yes, absolutely... and I would go even further...

[Interviewer] Yes? ...

[P8] In this society old people are over... are superfluous... their actions do not count, they must be set away... I think that our people are transformed... Formerly

people were polite... respectful, either to the milkman or to the grocery store attendant... or to the woman who sold the fish... and they also were the same... it was “do you need something, Master, or Miss...” Now we enter in a store and they look to us as they were looking to dolls... as they were saying... “for God sake, don’t come to bother me”...

[Interviewer] You are talking in general or regarding older people?

[P8] To most people is towards the elderly... Only when they see young people they behave differently... Because they think young people have more money... People judge by appearances... But some older people may also have the money to buy what they want... Formerly in the stores people would take everything out of the shelves to please us... And they weren’t happy if we were not satisfied... Not today... Total selfishness... It’s the granny it is not even worthy to look ...

[Interviewer] You mean society changed?

[P8] This society undervalues older people... Now we’re the grannies... people do not look at us...

[Interviewer] Why?

[P8] I think that some people were not prepared to have some social positions... It is not their fault... but they did not have the necessary education... it is the way children were brought up... this is education at home... foundations for good education are lost... Even some people in television... journalist or even politicians... they don’t even know how to correctly speak Portuguese... They are on such positions because the political party put them there ... not because they earned it... They do not have education, no nothing... they just care about the thousands they are receiving by the end of the month...

[Interviewer] So people changed?

[P8] All depends on foundations of a good education... at home... his character... if someone is respectful, educated, polite, correct... If someone was well

shaped... Some people are really not educated at all... They are able to give wrong advices... they just care to receive the salary at the end of the month...

[Interviewer] So education is important?

[P8] Yes... and respect... I was in Africa for some time, in the military service... and I had under my orders many black people who arrived without a pair of shoes, they could not read or write... even adult men... they often said “I do not understand this or that...” and I replied “you must learn to read... if you do you will be able to understand much more”... and I made many of them go to school... and many progressed in the military carrier. People learn... and superiors also learned to respect more as they were not only ignorant people... they are less arrogant as they know that down in line people are no full... Sometimes today in society some people think that because as they are in a superior position they are entitled to decide everything... and that we down here are just obliged to obey, to do whatever they say...

[Interviewer] By “we” you mean...

[P8] Elderly people. We do not have any power.

[Interviewer] Why?

[P8] When I look around I realize older people do not have any power in society... but they could have... if there was any political will... It is the will, the will... politicians should lose the arrogance... the haughtiness... they should look ... to structure society in order to avoid this look to «the little-poor-oldies », who do not know a thing... that can be manipulated as a flock.... As Salazar¹⁴ did... a flock of sheep¹⁵. But it is difficult to change starting from people because... unless a very important politician get really old... otherwise... we will stay... powerless.

[Interview ended by patient’s request]

¹⁴ Portuguese dictator in power from 1932 to 1968. He was responsible for the imposition of the fascist regime, also known in Portugal as «*Salazarism*».

¹⁵A jargon expression used to name a group of defenseless or submissive people.

Interview 2

[Interviewer] Yesterday we were talking about older people and autonomy but we also talked about power... I would like you to tell me about power, what power you have, what is power to you, in our life through the years...

[P8] Well, yes, I did have power a few times...

[Interviewer] Would you like to describe one of these occasions?

[P8] Well, when I went to work, arrived and the boss gave me the work to do, not only the tasks, but financial autonomy, power to make decisions, not only to make decisions but also to execute it... As a matter of fact, I believe that power is to plan and to do whatever decided... To decide and to do... as many people sometimes what the power just for show off... not to do things... They want to have a certificate of power, because they have the money or so...

[Interviewer] So you are meaning power at a professional level... and in private life?

[P8] In work power has different levels, it decreases down the line: the administrator, department directors, managers, and the workers... until the cleaning staff... Power has different levels and it is necessary to know how to use this power...

[Interviewer] So everyone has power?

[P8] In some extent yes... and people should get together to be stronger... not for violence or tyranny but to be stronger... But sometimes people loose power.

[Interviewer] Have you ever felt you have lost power?

[P8] Luckily not... well, yes, now here that I'm sick and here...

[Interviewer] As a patient in hospital? What kind of power do patients have in hospital?

[P8] Only a few patients in hospital have their own individual power... to ask for something or whatsoever... Patients should have power, should seek to have

power... as a citizen I think that I'm entitled to have it. Patients should require to be treated as... to be considered as partners... like colleagues... that's what I think...

[Interviewer] And you think that patients loose power?

[P8] Yes, I do! Patients often are under a certain professional despotism, authoritarianism... some physicians, some staff sometimes considered themselves outstanding... they think they are above everything and everyone. It is «I may, I want, I order...» it looks like we have to do whatever they say and keep quiet... and that's it! But no, we should not have to... It looks like when we come to the hospital is like we would not be able to think... Often people lose their power in hospital... I may have some power but they just want to push me through the door... they want us out as quickly as possible... they do not care to listen... And sometimes I try to cooperate with the medical team...

[Interviewer] Thus if the patient does not want something like taking a pill or having bath...what happens?

[P8] It is persuaded...

[Interviewer] Why?

[P8] Well they would try to persuade the person that it has to be done. But in a few circumstances is just a matter of organization...

[Interviewer] Could you give an example?

[P8] Bathing... it is not possible to have patients to bath all the day, one before lunch another after lunch... This should not be like... imposition but good management... it is important to explain to patients what are the rules and if the person is smart will understand that it is not possible to have people bathing all around the clock... Just because one wants it now and another one hour later... It must be explained that it is not imposition but organization, management...To oblige, to coerce... no thank you!

[Interviewer] It is different...

[P8] It is completely different, madam! We are not bullying people but we must say: look here in this place the rules are the following... there are rules in every place... at home we also have rules... in a democratic society there are rules and we must accept it as we accept the train schedule...

[Interviewer] Right...

[P8] As we accept all other kinds of rules...

[Interviewer] And if someone would come here and say «You must get up from bed now and to seat in the chair? And if you wouldn't feel like willing to do it...

[P8] They must understand and I must understand... If it is for my wellbeing, if it is useful in my condition...if it would be better for blood circulation...and if they explained me, I would understand that I have to get up from bed, or to bath... if explained... but not if it is just because they want or because they say... if they say «you have to stand up because I want to! ». If that is the case I do not accept it... But sometimes orders are out of mere caprice ... and it leads to conflict. It is not good! When someone imposes rules that nobody understand...

[Interviewer] It is not good...

[P8] If we do not understand it, it's because it is not explained... because we are not stupid...

[Interviewer] And from your experience... do you consider that rules are explained?

[P8] Generally they do not explain much... Not much!

[Interviewer] Why?

[P8] I don't know why... may be because they like to keep knowledge. The hierarchic chain, let's say it, they like to lead trumps¹⁶. People use knowledge to impose, because they are the ones who know... an example... if I'm a doctor... I decide that the patient will have surgery, but I do not say anything... Than the OR

¹⁶ Referring to the metaphor of playing cards and hiding the trump cards.

ring to the ward to call for the patient and nobody knew... And the poor patient? He will think: “why am I here in surgery? Why is this happening...? I am the right to know...” Particularly when patients have severe illness, they should have the right to know about their limitations... possible impairment.... It is extremely important... we have to talk about our life....

[Interviewer] You mean to be prepared?

[P8] Exactly! And step by step... Step by step and saying: look we are going to try this medication... we are not sure but we are going to try. It may be good, it may have consequences, but we are going to try... thus we would know...Patients should know exactly what is happening, step by step, what rules, what medications, what treatments... we should know.

[Interviewer] In order to give consent?

[P8] Exactly! And the patient will say if he wants to take the chance or not... Sometimes they have the protocol to inform and give us a form and say “Read this!” And we read it, but we feel so perplexed, that often we are unable to understand it, in that particular moment when we are reading... As often the language in the forms is mixed... current language and technical terms and we do not understand... and people think... “What a hell did he say?” After all, the most important thing is personal exchange. I think that it would be vital that nurses and doctors really tried to help patients understanding those things... the illness and all things...

[Interviewer] To help people to make decisions?

[P8] Yes...It is not just to give written information for patients and let them alone, trying to make sense of it, No! It is the personal touch, the way to approach people... The way to lead to the understanding of a situation. It is more than just giving a paper to sign... It would make all difference! And this is it!

[Interview ended by patient’s request]

APPENDIX 7

**ETHICAL CONTRACT SIGNED BY ALL PARTICIPANTS
IN THE BIOGRAPHIC APPROACH SEMINAR - PORTUGUESE VERSION**



4º Curso de Complemento de Formação em Enfermagem
Disciplina de Enfermagem

Seminário de Abordagem Biográfica

Contrato ético

Entre o grupo de participantes (incluindo a professora)

1. Cada um/a compromete-se a não divulgar as vivências e a experiências que forem partilhadas durante a formação
2. cada um/a compromete-se a não utilizar em qualquer contexto as informações às quais teve acesso durante a formação, o que inclui pressionar directa ou indirectamente uma pessoa
3. cada um compromete-se a não utilizar ou deixar à vista, em qualquer circunstância ou lugar, as narrativas escritas, nem a fazer reprodução total ou parcial por qualquer meio
4. no final da formação os participantes decidem entre eles o fim a dar à sua narrativa escrita
5. Dulce Cabete, enquanto professora desta área temática, solicita a cada participante uma cópia da sua narrativa escrita, na data definida. Esse exemplar será guardado no seu arquivo pessoal, com o compromisso de nunca o utilizar com terceiras pessoas, em público ou em privado. A professora poderá, contudo, evocar certas situações ou acontecimentos, a título de exemplo, mas sem revelar qualquer detalhe que permita a identificação da pessoa em causa.

Setúbal, 18 de Março de 2005

Alzira de Brito Santiago

José

Saúl Ferreira Marques

Ana Teresa Marques

Deolinda Gomes Duarte

Mendes

Caraca Correia

Filipe de Oliveira

Luís Manuel Rodrigues Mendes Antunes

Kauzilio

Silvia Pereira Gomes Razeiro

Silvia Ferreira

Luís António de Sousa Brito

António José

Ana de Jesus F. Ribeiro Baião

Suzi Almeida

Ana Carolina de Jesus

Carvalho Marques

Isabel Lopes

Arabela Din

Dulce Cabete

APPENDIX 8

INFORMED CONSENT FOR USING PERSONAL MATERIAL

INFORMED CONSENT - NURSES

My name is Dulce Cabete and I'm post-graduate researcher at the Northumbria University at Newcastle (England) carrying out a research in the field of Gerontological Nursing. The aim of the research is to explore autonomy concept and empowerment process in hospitalised older people. Therefore I'm collecting data through biographic approach, encompassing oral narrative, written narrative, and an in-depth interviewing. During group discussions I will also be taking notes. I would like to ask for your cooperation, abiding by the following principles:

1. Your participation is voluntary ;
2. You are free to withdraw at any time;
3. There won't be any benefits or penalties for participation, refusal or withdrawing;
4. As we are searching for knowledge that might contribute to best nursing practices you're asked to be truthful and reflexive however you are not obliged to say anything against your will;
5. If you will feel uncomfortable at any time please let me know to stop interviewing;
6. I need to do an audio record of interviews but you may ask to stop recording whenever you want;
7. The recorder material won't be available to anyone else besides the researcher and the University Supervisors and will be deleted after transcription and authorization from the University;
8. During Biographic Approach Seminar you will be asked to write a diary or reflexive notes;
9. All written material will be exclusively used for the purpose of the present research and will be kept in a secure place;
10. Your identity as well as any detail that might reveal it will remain confidential;

11. Group discussion about the process and its findings might bring someone to share a private experience. No one will be induced to disclose private issues. However if this occurs colleagues will consider it as professionally classified information.
12. The results of this study will be published. Although all material collected will remain confidential, some excerpts might be used without revealing the author's identity.

Due to the underlying philosophy of phenomenological methodology and biographic approach participants are considered as co-researchers with a joint responsibility of searching for the meaning of autonomy and empowerment process through life experiences' narratives. Thus this informed consent assumes an ethical contract from within which each and every participant (researcher included) plays an active role.

I declare that:

- a) I understood research's aim and its underlying principles
- b) The researcher explained to me every topic and answered all my questions
- c) I agree to participate in this study

Setúbal, ___/___/_____

Signature: _____

APPENDIX 9

INFORMED CONSENT FOR USING PERSONAL MATERIAL - PORTUGUESE TRANSLATION

CONSENTIMENTO INFORMADO - ENFERMEIRAS

Chamo-me Dulce Cabete e sou Investigadora Pós-Graduada na Northumbria University at Newcastle (Inglaterra) e estou a realizar uma investigação no campo da enfermagem gerontológica. O objectivo desta investigação é explorar o conceito de autonomia e o processo de empowerment em pessoas idosas hospitalizadas. Para isso, estou a recolher dados através da abordagem biográfica, englobando narrativas orais, narrativas escritas e entrevistas exploratórias. Durante as sessões de grupo poderei também tomar notas. Gostaria, assim, de solicitar a sua colaboração, respeitando os seguintes princípios:

1. A sua participação é voluntária;
2. Pode desistir de participar em qualquer altura;
3. Da participação, recusa ou desistência não decorrerão quaisquer benefícios ou penalizações;
4. Uma vez que procuramos conhecimento que pode vir a contribuir para melhorar as práticas de enfermagem, é-lhe pedido que seja verdadeiro(a) e reflexivo (a); contudo, não se sinta obrigado(a) a dizer algo que não queira;
5. Se o desejar, pode solicitar a interrupção da entrevista em qualquer altura;
6. A entrevista terá que ser gravada, mas pode solicitar, em qualquer altura, a interrupção da gravação;
7. O material gravado não estará disponível para mais ninguém para além da investigadora e dos orientadores da universidade e será destruído depois da transcrição e de autorização da Universidade;
8. Durante o Seminário de Abordagem Biográfica ser-lhe-á pedido que escreva um diário ou notas de reflexão pessoal;
9. Todo o material escrito só será utilizado para esta investigação e será guardado em lugar seguro;

10. A sua identidade, bem como qualquer detalhe que a possa revelar, será confidencial;
11. Nas sessões de discussão em grupo, de análise e interpretação do processo e dos resultados, pode ocorrer a partilha de experiências pessoais. Ninguém é obrigado a fazê-lo mas, se tal ocorrer, os colegas considerá-la-ão informação confidencial, ao abrigo do sigilo profissional;
12. Os resultados deste estudo serão publicados e, embora todo o material recolhido permaneça confidencial, alguns excertos poderão ser usados, sem revelar a identidade do seu autor.

Dada a filosofia subjacente à fenomenologia e à abordagem biográfica, os participantes são considerados co-investigadores, com a responsabilidade conjunta de procurar o sentido da autonomia e do processo de empowerment através das narrativas de experiências vividas. Assim, este consentimento informado assume também a forma de um contrato ético, no qual cada participante (investigador incluído) desempenha um papel activo.

Declaro que:

- a) Compreendi o objectivo da investigação e os princípios subjacentes à mesma;
- b) A investigadora explicou-me todos os tópicos e respondeu a todas as minhas questões;
- c) Concordo em participar neste estudo.

Data ___/___/___ Assinatura: _____

APPENDIX 10

**INFORMED CONSENT TO INTERVIEW:
BILLING VERSION**

INFORMED CONSENT (Consentimento informado)

NURSES (Enfermeiros/as)

My name is Dulce Cabete and I'm post-graduate researcher at the Northumbria University at Newcastle (England) carrying out a research in the field of Gerontological Nursing.

The aim of the research is to explore autonomy concept and empowerment process in hospitalised older people.

Therefore I'm collecting data through biographic approach, encompassing oral narrative, written narrative, and an in-depth interviewing. During group discussions I will also be taking notes. I would like to ask for your cooperation, abiding by the following principles:

1. Your participation is voluntary ;
2. You are free to withdraw at any time;
3. There won't be any benefits or penalties for participation, refusal or withdrawing;
4. As we are searching for knowledge that might contribute to best nursing practices you're asked to be truthful and reflexive however you are not obliged to say anything against your will;
5. If you will feel uncomfortable at any time please let me know to stop interviewing;
6. I need to do an audio record of interviews but you may ask to stop recording whenever you want;
7. The recorder material won't be available to anyone else besides the researcher and the University Supervisors and will be deleted after transcription and authorization from the University;
8. During Biographic approach Seminar you will be asked to write a diary or reflexive notes;

Chamo-me Dulce Cabete e sou Investigadora Pós-graduada na Northumbria University at Newcastle (England) e estou a realizar uma investigação no campo da enfermagem gerontológica.

O objectivo desta investigação é explorar o conceito de autonomia e o processo de empowerment em pessoas idosas hospitalizadas.

Para isso, estou a recolher dados através da abordagem biográfica, englobando narrativas orais, narrativas escritas e entrevistas exploratórias. Durante as sessões de grupo poderei também tomar notas. Gostaria, assim, de solicitar a sua colaboração, respeitando os seguintes princípios:

1. A sua participação é voluntária ;
2. Pode desistir de participar em qualquer altura;
3. Da participação, recusa ou desistência não decorrerão quaisquer benefícios ou penalizações;
4. Uma vez que procuramos conhecimento que pode vir a contribuir para melhorar as práticas de enfermagem, é-lhe pedido que seja verdadeiro(a) e reflexivo(a); contudo, não se sinta obrigado(a) a dizer algo que não queira;
5. Se o desejar, pode solicitar a interrupção da entrevista em qualquer altura;
6. A entrevista terá que ser gravada, mas pode solicitar, em qualquer altura, a interrupção da gravação;
7. O material gravado não estará disponível para mais ninguém para além da investigadora e dos orientadores da universidade e será destruído depois da transcrição e de autorização da Universidade;
8. Durante o Seminário de Abordagem Biográfica ser-lhe-á pedido que escreva um diário ou notas de reflexão pessoal;

- | | |
|--|---|
| <p>9. All written material will be exclusively used for the purpose of the present research and will be kept in a secure place;</p> <p>10. Your identity as well as any detail that might reveal it will remain confidential;</p> <p>11. Group discussion about the process and its findings might bring someone to share a private experience. No one will be induced to disclose private issues. However if this occurs colleagues will consider it as professionally classified information.</p> <p>12. The results of this study will be published. Although all material collected will remain confidential, some excerpts might be used without revealing the author's identity.</p> | <p>9. Todo o material escrito só será utilizado para esta investigação e será guardado em lugar seguro;</p> <p>10. A sua identidade, bem como qualquer detalhe que a possa revelar, será confidencial;</p> <p>11. Nas sessões de discussão em grupo, de análise e interpretação do processo e dos resultados, pode ocorrer a partilha de experiências pessoais. Ninguém é obrigado a fazê-lo mas, se tal ocorrer, os colegas considerá-la-ão informação confidencial, ao abrigo do sigilo profissional;</p> <p>12. Os resultados deste estudo serão publicados e, embora todo o material recolhido permaneça confidencial, alguns excertos poderão ser usados, sem revelar a identidade do seu autor.</p> |
|--|---|

Due to the underlying philosophy of phenomenological methodology and biographic approach participants are considered as co-researchers with a joint responsibility of searching for the meaning of autonomy and empowerment process through life experiences' narratives.

Dada a filosofia subjacente à fenomenologia e à abordagem biográfica, os participantes são considerados co-investigadores, com a responsabilidade conjunta de procurar o sentido da autonomia e do processo de empowerment através das narrativas de experiências vividas.

Thus this informed consent assumes an ethical contract from within which each and every participant (researcher included) plays an active role.

Assim, este consentimento informado assume também a forma de um contrato ético, no qual cada participante (investigador incluído) desempenha um papel activo.

I declare that:

- a) I understood research's aim and its underlying principles;
- b) The researcher explained to me every topic and answered all my questions;
- c) I agree to participate in this study.

Declaro que:

- a) Compreendi o objectivo da investigação e os princípios subjacentes à mesma;
- b) A investigadora explicou-me todos os tópicos e respondeu a todas as minhas questões;
- c) Concordo em participar neste estudo.

Setúbal, 15/12/2025

Signature (Assinatura): Shirley Maria do Faleiro Teixeira Lopes

APPENDIX 11

**INFORMED CONSENT – PATIENT’S FORM:
ENGLISH TRANSLATION**

INFORMED CONSENT

PATIENTS

My name is Dulce Cabete and I'm post-graduate researcher at the Northumbria University at Newcastle (England) carrying out a research in the field of Older Peoples' Nursing. The aim of the research is to explore the autonomy concept and empowerment process in hospitalised older people. Therefore I'm collecting data through 3 individual interviews, the first two in hospital and the third one at participant's home. I would like to ask your cooperation, abiding by the following principles:

1. your participation is absolutely voluntary ;
2. you are free to withdraw at any time;
3. there won't be any benefits or penalties for participation, refusal or withdrawing;
4. participation or refusal won't interfere in medical or nursing care;
5. as I am searching for knowledge that might contribute for best nursing practices you're asked to be truthful and reflexive however you are not obliged to say anything against your will;
6. if you will feel uncomfortable at any time please let me know to stop interviewing;
7. I need to do an audio record of this interview but you may ask to stop recording whenever you want;

8. the recorder material won't be available to anyone else besides the researcher and the University Supervisors and will be deleted after transcription and authorization from the University;
9. All written material will be exclusively used for the purpose of the present research and will be kept in a secure place;
10. Your identity as well as any detail that might reveal it will remain confidential;
11. The results of this study will be published. Although interviews transcriptions will remain confidential, some excerpts might be used without revealing the author's identity.

I declare that:

- a) I understood research's aim and its underlying principles
- b) The researcher explained to me every topic and answered all my questions
- c) I agree to participate in this study

Setúbal, ____/____/_____

Signature: _____

APPENDIX 12

INFORMED CONSENT – PATIENT’S FORM: PORTUGUESE VERSION SIGNED BY PATIENTS

Consentimento livre e esclarecido

Pessoas Idosas

O meu nome é Dulce Cabete e sou investigadora pós-graduada na Universidade de Northumbria, em Newcastle, Inglaterra. Estou a fazer uma investigação na área da Gerontologia (processo de envelhecimento).

O objectivo desta investigação é explorar o conceito de autonomia e o processo de empowerment nas pessoas idosas hospitalizadas. Para isso estou a entrevistar pessoas que têm mais de 65 anos e que estão internadas neste serviço. Gostaria de pedir a sua colaboração, de acordo com os seguintes princípios:

- A sua participação é absolutamente voluntária;
- É livre de desistir a qualquer altura;
- Não haverá qualquer recompensa ou prejuízo por participar, recusar ou desistir;
- A participação ou a recusa não terá qualquer consequência nos cuidados médicos ou de enfermagem;
- Uma vez que estou a recolher informação que tem em vista melhorar as práticas de enfermagem, é-lhe solicitado que seja verdadeiro e que reflecta comigo nas questões que lhe vou colocar. Contudo, não se sinta obrigado a dizer alguma coisa que não queira;

- Se se sentir mal ou desconfortável a qualquer momento, por favor diga que interrompemos a entrevista;
- Eu preciso de gravar esta entrevista, mas a gravação poderá ser interrompida a qualquer momento, de acordo com a sua vontade;
- As gravações serão para meu uso exclusivo nesta investigação e ninguém terá acesso a elas. As gravações serão apagadas depois de transcritas e de haver autorização da Universidade;
- Todo o material recolhido será para uso exclusivo desta investigação e será guardado em lugar seguro:
- A sua identidade, bem como qualquer detalhe que a possa identificar serão mantidos em estrita confidencialidade;
- Os resultados deste estudo serão publicados, no entanto as transcrições das entrevistas serão mantidas confidenciais. Poderão ser apenas utilizados alguns extractos sem revelar a identidade do autor.

Declaro que:

- a) Compreendi o objectivo da investigação e os seus princípios básicos;**
- b) A investigadora explicou-me todos os tópicos e respondeu a todas as minhas questões;**
- c) Concordo em participar neste estudo.**

Data ____/____/2006 Assinatura_____

APPENDIX 13

INFORMED CONSENT – PATIENTS’ FORM: LARGE PRINT FOR VISUALLY IMPAIRED PERSONS

Consentimento livre e esclarecido

Pessoas Idosas

O meu nome é Dulce Cabete e sou investigadora pós-graduada na Universidade de Northumbria, em Newcastle, Inglaterra. Estou a fazer uma investigação na área da Gerontologia (processo de envelhecimento).

O objectivo desta investigação é explorar o conceito de autonomia e o processo de empowerment nas pessoas idosas hospitalizadas. Para isso estou a entrevistar pessoas que têm mais de 65 anos e que estão internadas neste serviço. Gostaria de pedir a sua colaboração, de acordo com os seguintes princípios:

- A sua participação é absolutamente voluntária;
- É livre de desistir a qualquer altura;
- Não haverá qualquer recompensa ou prejuízo por participar, recusar ou desistir;
- A participação ou a recusa não terá qualquer consequência nos cuidados médicos ou de enfermagem;
- Uma vez que estou a recolher informação que tem em vista melhorar as práticas de enfermagem, é-lhe solicitado que seja verdadeiro e que reflecta comigo nas questões que lhe vou colocar. Contudo, não se sinta obrigado a dizer alguma coisa que não queira;

- Se se sentir mal ou desconfortável a qualquer momento, por favor diga que interrompemos a entrevista;
- Eu preciso de gravar esta entrevista, mas a gravação poderá ser interrompida a qualquer momento, de acordo com a sua vontade;
- As gravações serão para meu uso exclusivo nesta investigação e ninguém terá acesso a elas. As gravações serão apagadas depois de transcritas e de haver autorização da Universidade;
- Todo o material recolhido será para uso exclusivo desta investigação e será guardado em lugar seguro:

- A sua identidade, bem como qualquer detalhe que a possa identificar serão mantidos em estrita confidencialidade;
- Os resultados deste estudo serão publicados, no entanto as transcrições das entrevistas serão mantidas confidenciais. Poderão ser apenas utilizados alguns extractos sem revelar a identidade do autor.

Declaro que:

a) Compreendi o objectivo da investigação e os seus princípios básicos;

b) A investigadora explicou-me todos os tópicos e respondeu a todas as minhas questões;

c) Concordo em participar neste estudo.

Data ____/____/2006

Assinatura _____

APPENDIX 14

**CRIMINAL CONVICTIONS CERTIFICATE
ENGLISH TRANSLATION**

**THE PORTUGUESE REPUBLIC
MINISTRY OF JUSTICE
GENERAL BUREAU OF JUSTICE**

CRIMINAL CONVICTIONS RECORD

Name: DULCE DOS SANTOS GASPAR CABETE

Native of the Civil Parish of: SANTO ILDEFONSO

County Council of: PORTO

Date of birth: 1961/12/12

Nationality: PORTUGUESE

Identity Card: 3983415

Other documents of identification:-----

Certificate required by: -----

Petitioner:-----

Identity document number: -----

For the purpose of: SETTING IN A FOREIGN COUNTRY

NOTHING IS REPORTED ABOUT THE PERSON ABOVE IDENTIFIED

Day of the issue 2005/02/22

Control RCPA60/0222/091535

Criminal Service Bureau

APPENDIX 15

**ETHICAL APPROVAL FROM
UNN SCHOOL'S ETHICS SUB-COMMITTEE**

17 May 2005

Dulce Santos Gaspar Cabete
Rua Natalia Correia
9 - 2º DTO
2810 - 329 Almada
PORTUGAL

Dear Dulce

School of HCES Research Ethics Sub Committee

Title: Autonomy concept and empowerment process in hospitalised older people

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and that the University Policies on Ethics and Consent are followed.

You may now also proceed with your application (if applicable) to:

- NHS organisations for Trust approval where appropriate.
- Local Research Ethics Committee (LREC), or Multi-Centred Research Ethics Committee (MREC).
[Please forward a copy of this letter where appropriate plus the peer reviewers comments and your response to those comments.]

IMPORTANT: PLEASE FORWARD A COPY OF YOUR LREC/MREC APPROVAL LETTER TO THE ABOVE ADDRESS.

- Please also agree honorary contract(s) with Trusts where appropriate. **Please forward a copy of any agreed honorary contracts to the above address.** Note that occupational health and criminal records bureau clearance may also be required.
- The above Committee would be willing to forward the independent peer review form to relevant R&D NHS Trusts/LREC/MREC upon receipt of a signed request from yourself.

All researchers must also notify this office of the following:

- Commencement and completion of the study;
- Any significant changes to the study design;
- Any adverse effects on participants or staff;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely



Tina Cook

APPENDIX 16

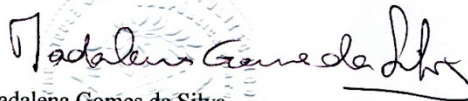
**ETHICAL APPROVAL FROM HEALTH SUPERIOR SCHOOL OF SETÚBAL
– PORTUGAL**



ESCOLA SUPERIOR DE SAÚDE
INSTITUTO POLITÉCNICO DE SETÚBAL
HUMANISMO, QUALIDADE E INOVAÇÃO

TO WHOM IT MAY CONCERN

This is to certify that the lecturer Dulce Cabete has presented to this Committee her PhD Project Proposal, discriminating all clinical and ethical procedures, and that it has been accepted without any further recommendations.



Madalena Gomes da Silva
President of the Scientific Committee

APPENDIX 17

**REQUEST FOR DATA COLLECTION WITH PATIENTS
TO ADMINISTRATION BOARD OF
HOSPITAL GARCIA DE ORTA – PORTUGAL**

Dulce Gaspar Cabete

R. Natália Correia, 9-2º Dto
2810 – 418 ALMADA
Tel: 91 477 63 80
e-mail: dulce.cabete@unn.ac.uk

Exmo. Sr.
Presidente do Conselho de Administração
do Hospital Garcia de Orta

Almada, 2 de Maio de 2006

Assunto: Pedido de autorização para recolha de dados para tese de doutoramento

Na qualidade de investigadora pós-graduada da Northumbria University at Newcastle (UNN), Inglaterra, estou a realizar um trabalho de investigação sobre o processo de empowerment das pessoas idosas hospitalizadas, integrado no projecto de Doutoramento em Ciências de Enfermagem. Trata-se de um estudo qualitativo, de abordagem fenomenológica, cujo objectivo é o desenvolvimento de um modelo de empowerment das pessoas idosas.

Os participantes deste estudo serão pessoas idosas (com mais de 65 anos) hospitalizadas há mais de 72h, sem deficit cognitivo significativo (utilizando-se para isso a escala de avaliação MMS, de *Folstein e colaboradores*, com o *cut point* de 24) e com a capacidade de falar durante cerca de uma hora sem consequências previsíveis no seu estado clínico (segundo avaliação da enfermeira responsável).

A recolha de dados será feita através de entrevistas de abordagem biográfica, não estruturadas, estando previstas 3 entrevistas por participante, duas das quais durante o internamento e uma após a alta, para construção da história de vida do participante em torno de experiências de hospitalização. A realização de entrevistas terá como limite a saturação de dados. A análise dos dados será feita com recurso à fenomenologia hermenêutica.

Comprometo-me a respeitar todos os princípios éticos de investigação, nomeadamente o consentimento livre e esclarecido, o direito ao abandono do estudo em qualquer momento, a confidencialidade das fontes, a não maleficência, tal como se encontra descrito na folha de consentimento informado que se junta (o consentimento será obtido apenas em língua portuguesa e estarão disponíveis impressões em tamanho de letra aumentado para pessoas com dificuldades de visão). Em anexo encontra-se também a aprovação do projecto de investigação pela Comissão de Ética da UNN. Comprometo-me, ainda, a entregar ao CA do HGO um exemplar da tese, depois de concluída e de obtida a autorização da UNN.

Venho, assim, solicitar a V^ª Ex.^ª autorização para a referida recolha de dados. O Serviço pretendido para o efeito é o Serviço de Cardiologia. As razões da escolha estão relacionadas com o conhecimento prévio que detenho sobre o serviço – elevada prevalência de pessoas idosas com capacidades cognitivas mantidas e sem problemas neurológicos relevantes – o que corresponde ao perfil pretendido.

Estarei ao dispor para prestar todos os esclarecimentos necessários, agradecendo, desde já, toda a atenção dispensada. Tratando-se de um trabalho realizado numa instituição inglesa, junto esta mesma carta em inglês, na qual solicito o vosso despacho.

Com os melhores cumprimentos

Dulce Gaspar Cabete
R. Natália Correia, 9-2º Dto.
2810 – 418 ALMADA
Portugal
Tel.: 91 477 63 80
e-mail: dulce.cabete@unn.ac.uk

Dear Mr. President of the
Administration Board of
Hospital Garcia de Orta

Date: 2nd of May 2006

Subject: Request for data collecting approval to PhD thesis

As Post-Graduate researcher at Northumbria University at Newcastle (UNN), England, I'm developing a case study of the empowerment process of hospitalised older people, as part of my PhD project in Nursing Sciences. It is a qualitative study with a phenomenological approach. The aim of this study is to draw a model of empowerment of hospitalised older people.

Participants will be older adults (over 65 years old), having at least 72h of hospitalization, without significant cognitive impairment (according to Mini Mental State Examination, by Folstein et al, at the cut point of 24) and being able to talk for just over one hour without predictable damage on their clinical condition (according to primary nurse clinical judgement).

Data will be collected in the course of 3 biographic in depth unstructured interviews (2 at hospital and 1 after discharge) to build participant's life history around hospitalisation experiences. The recruitment will proceed until data saturation is achieved. Data analysis and interpretation will be done by hermeneutical phenomenology.

I'll abide by all ethical research principles, namely free and informed participation, the right to quit or drop out at any point of the research progress, confidentiality, non-maleficence as written at the informed consent form attached to this letter (the informed consent will be signed just in Portuguese and large prints will be available to poor sight participants). You can also find attached a copy of UNN's Ethics Sub-Committee approval. I will also address to Hospital's Administration Board one copy of the research report, after its conclusion and UNN's authorisation.

Thus, I'm asking your permission to do data collection in Cardiology Department. The reasons of my choice are related to previous knowledge of this ward as having high prevalence of unimpaired hospitalised older people (without cognitive impairment or neurological pathology) who fits in participants profile.

I will be glad to meet you in order to answer to any queries.

Thank you very much for your time and attention.

Best regards,

APPENDIX 18

**AUTHORIZATION FROM ADMINISTRATION BOARD OF
HOSPITAL GARCIA DE ORTA – PORTUGAL**

Nossa ref.
our ref. 13.06.2006*008073

vossa ref.
your ref.

data
date

assunto
subject

Exm^a. Senhora
D. Dulce Gaspar Cabete
R. Natália Correia, 9 – 2^o.Dt^o.
2810 - 418 ALMADA

Em resposta ao vosso pedido de 2 de Maio de 2006, informamos que está autorizada a pesquisa no âmbito do Doutoramento em Ciências de Enfermagem no Serviço de Cardiologia do Hospital Garcia de Orta EPE.

Com os melhores cumprimentos. 

A Enfermeira Directora

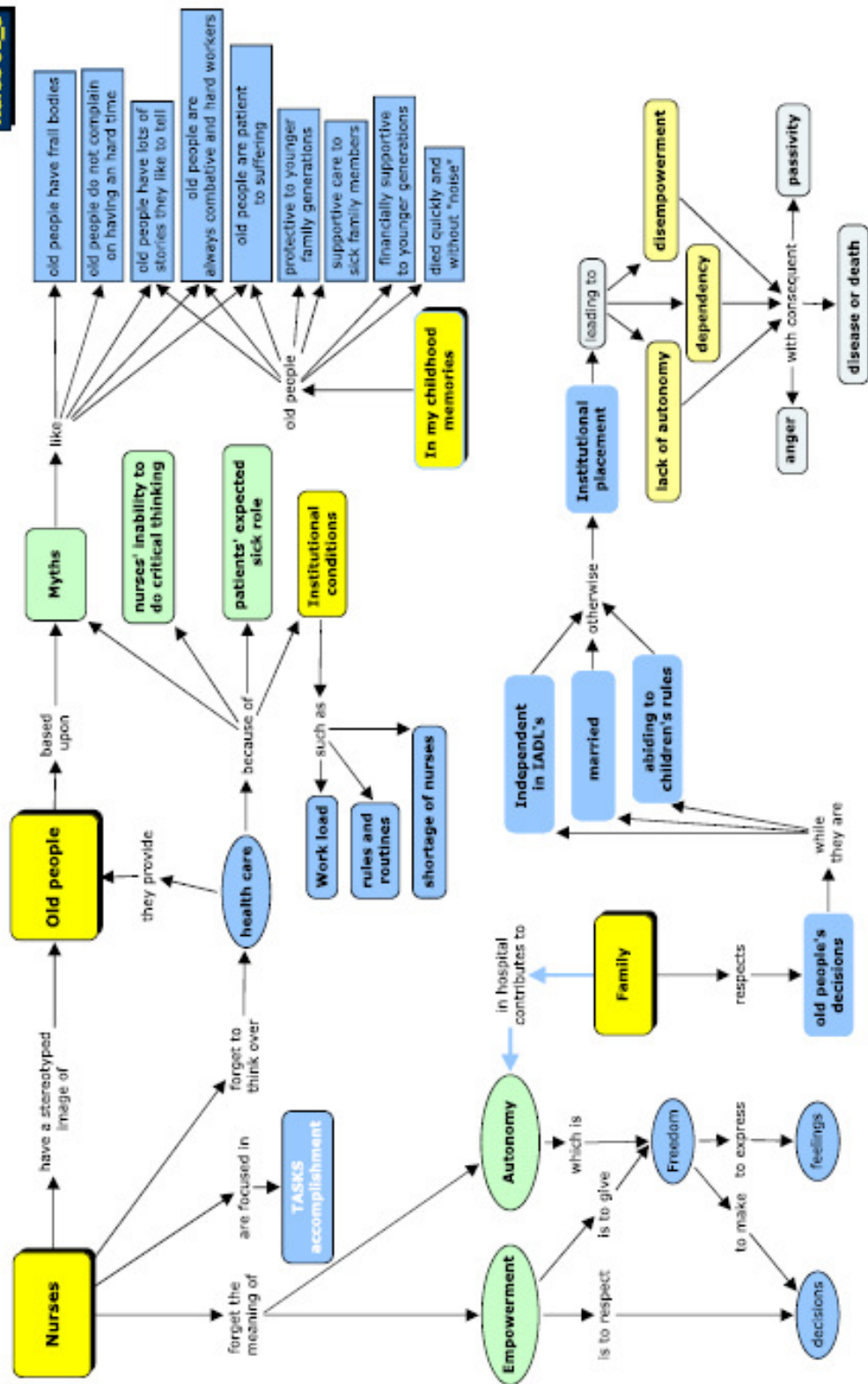

A Enfermeira Directora
ODÍLIA NEVES

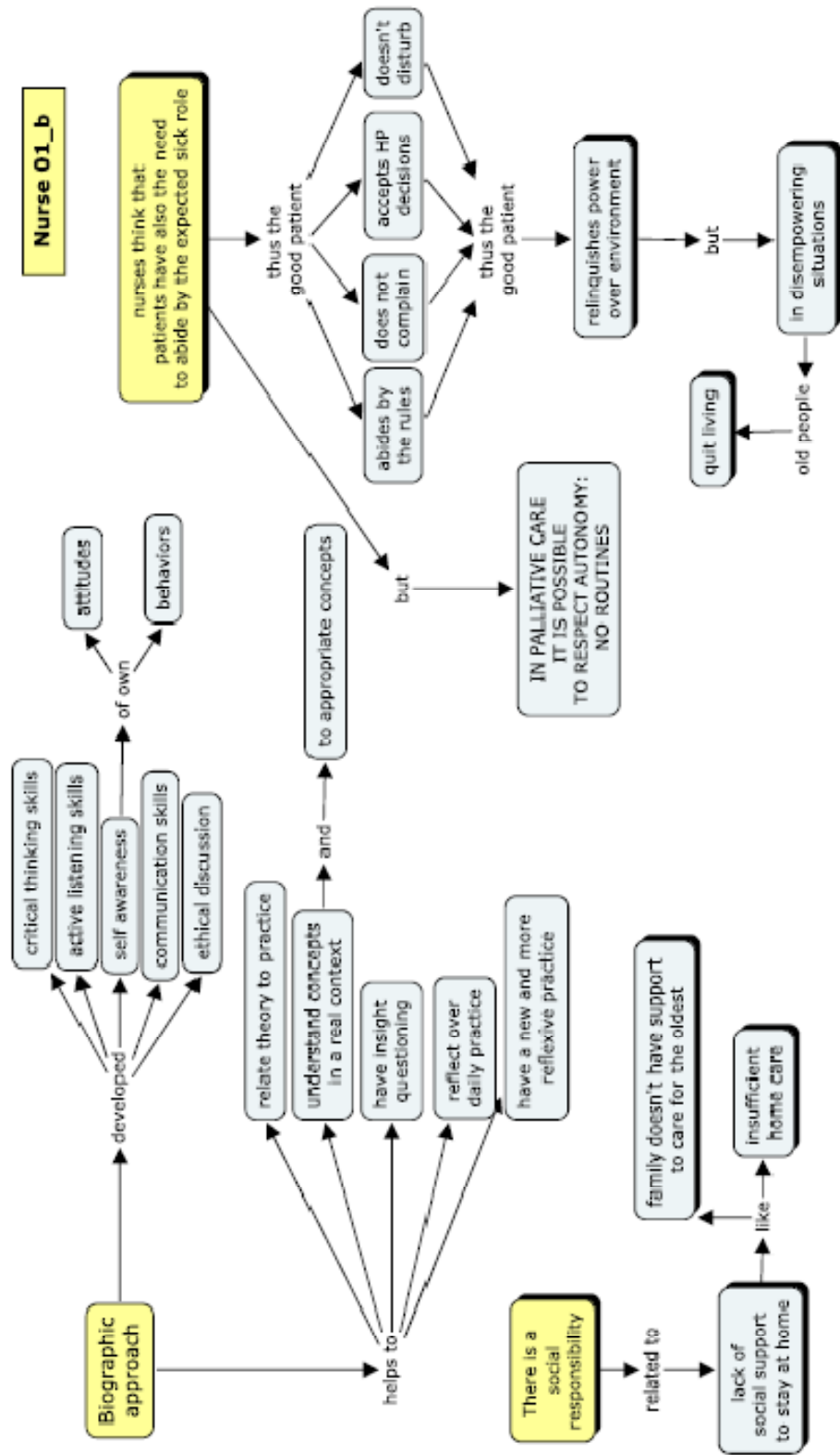
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APPENDIX 19

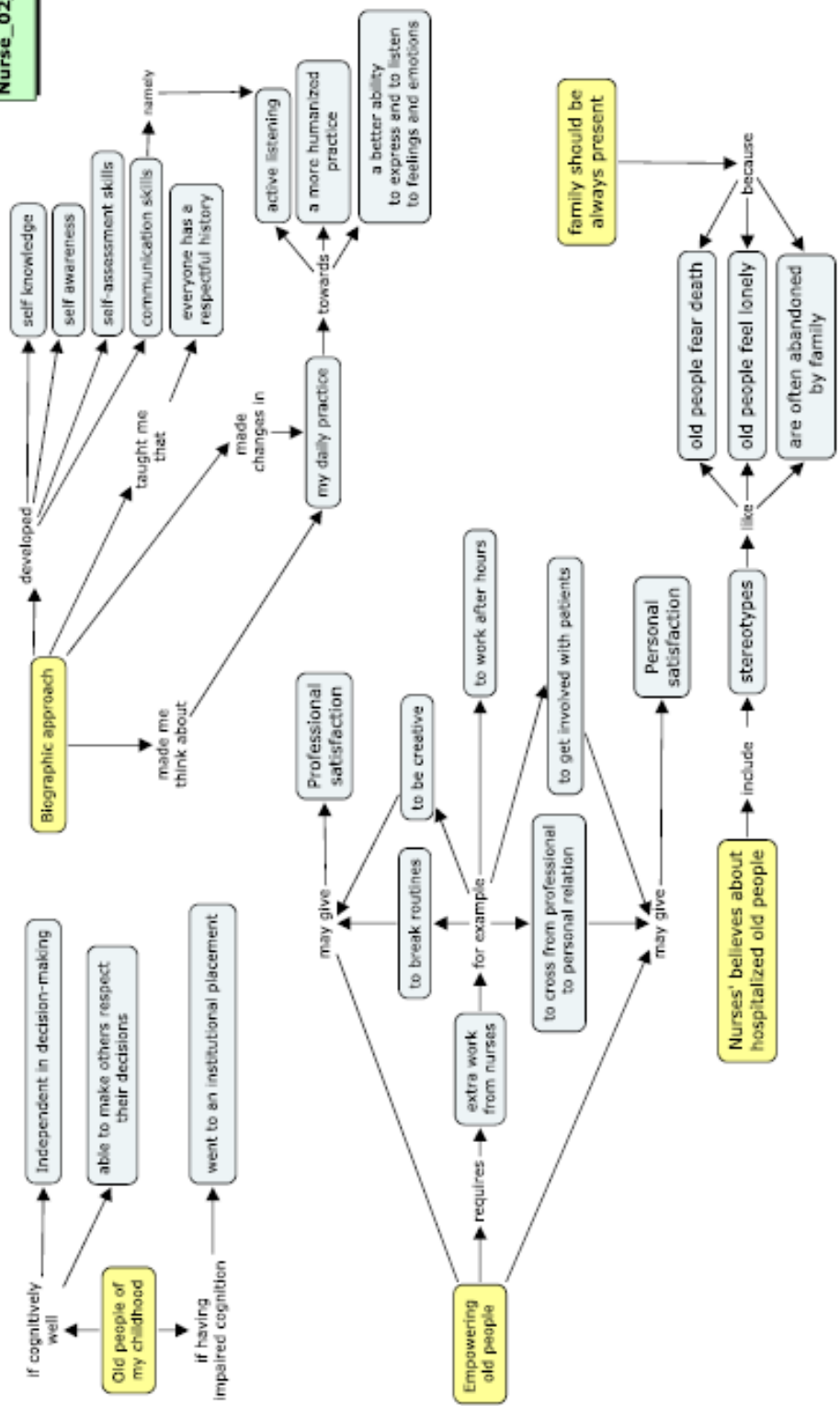
NURSES' CONCEPTUAL MAPS

Nurse 01_a

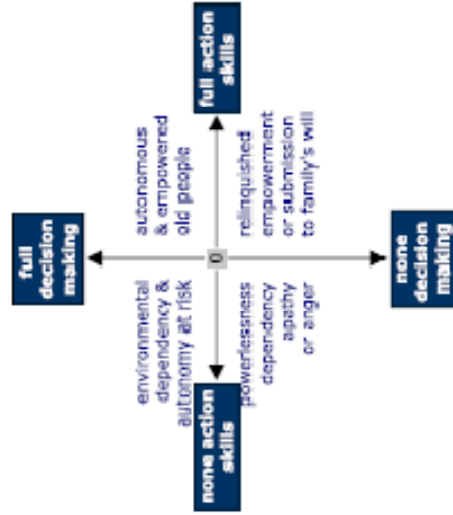




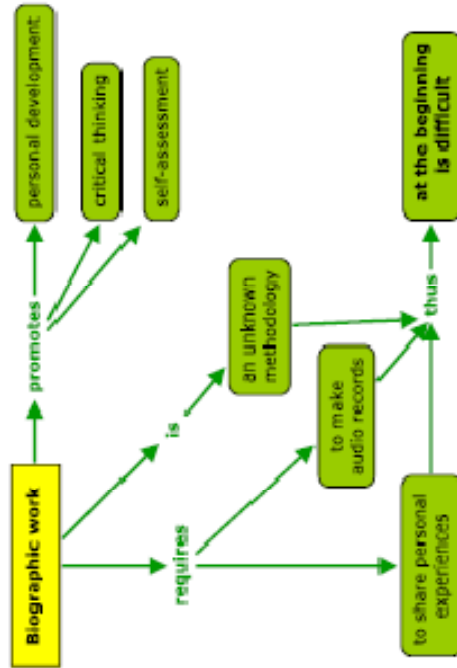
Nurse_02_a



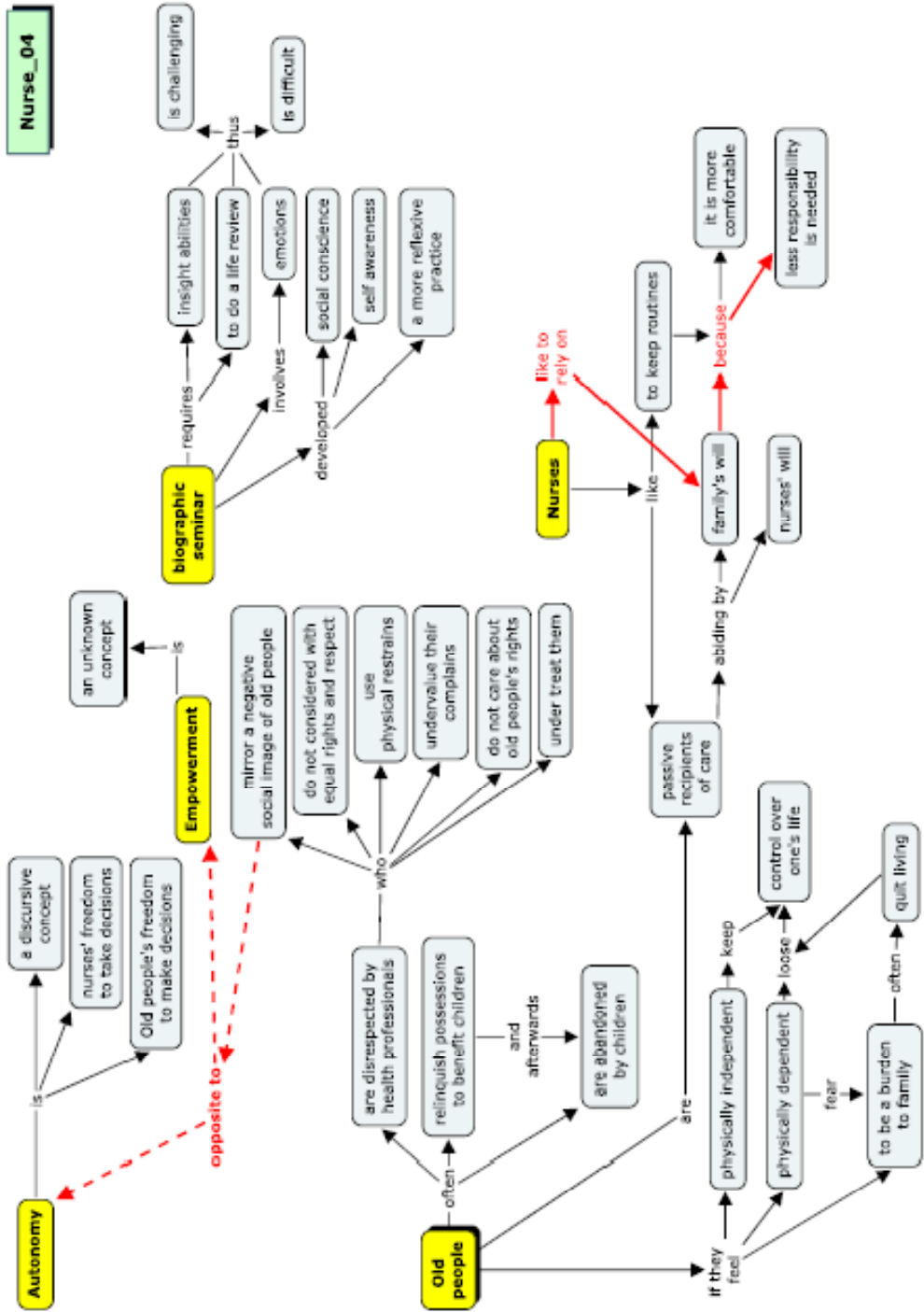
Nurse_03b

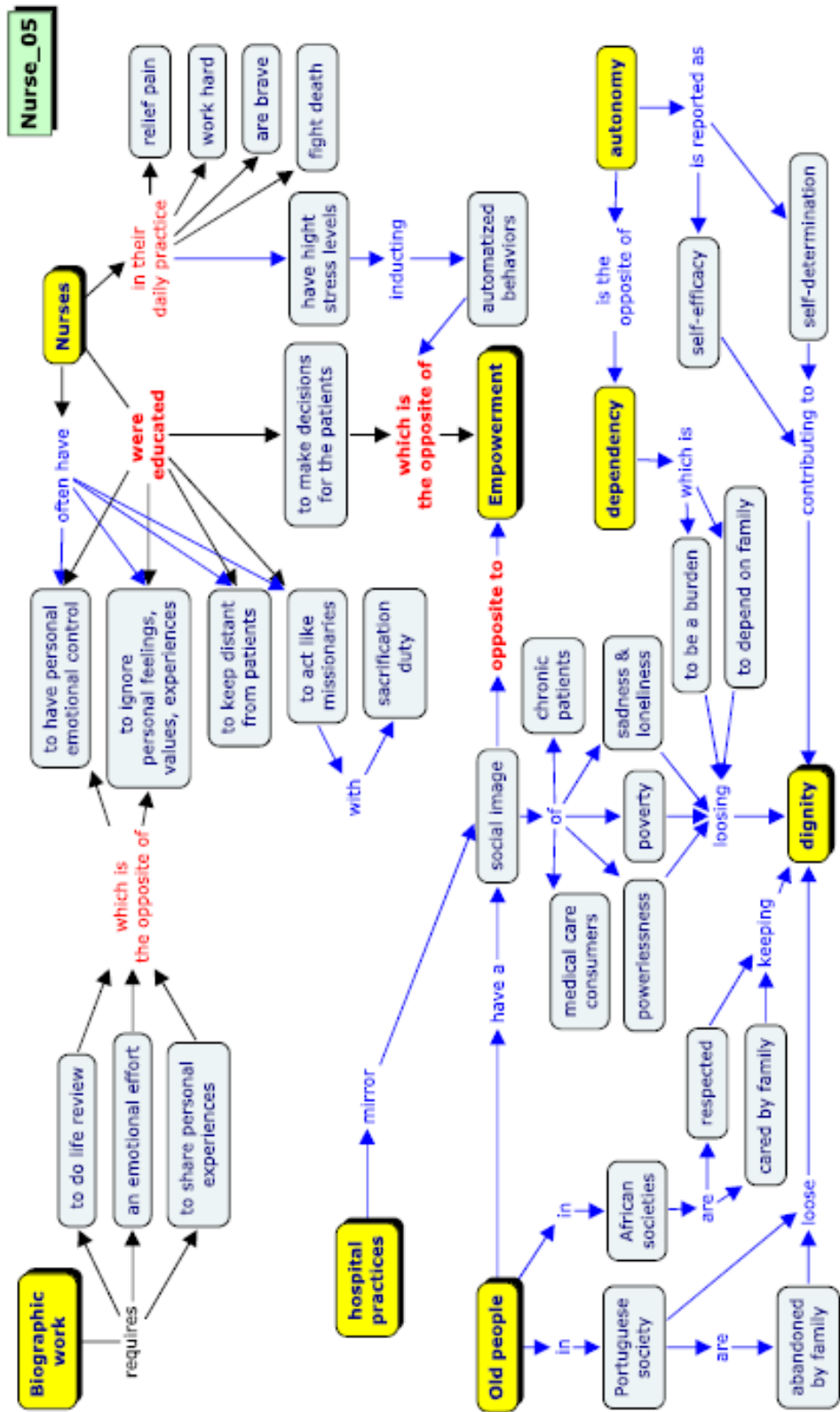


Autonomy is to decide and to do...
Empowerment is the careers' action in autonomy impairment situations!

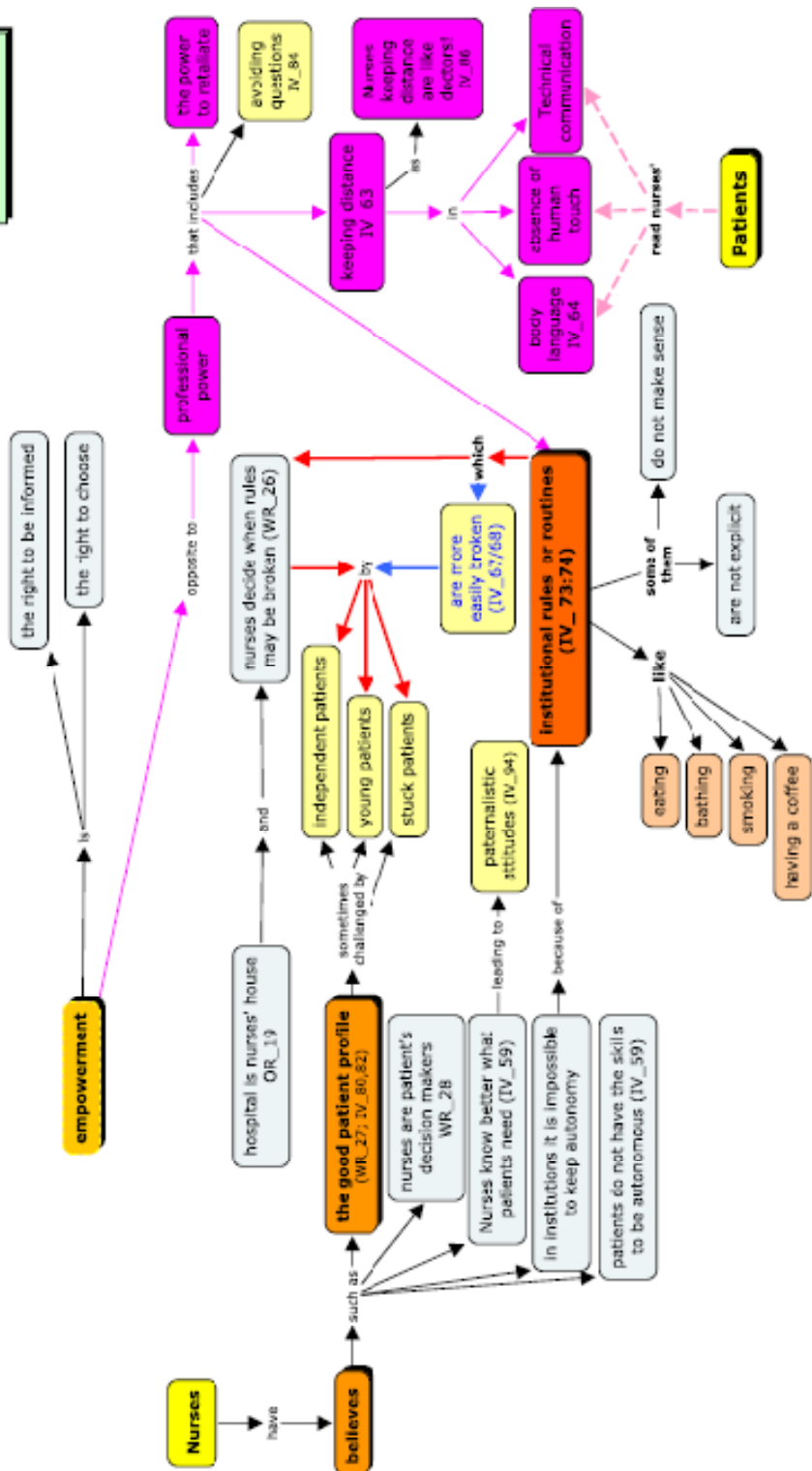


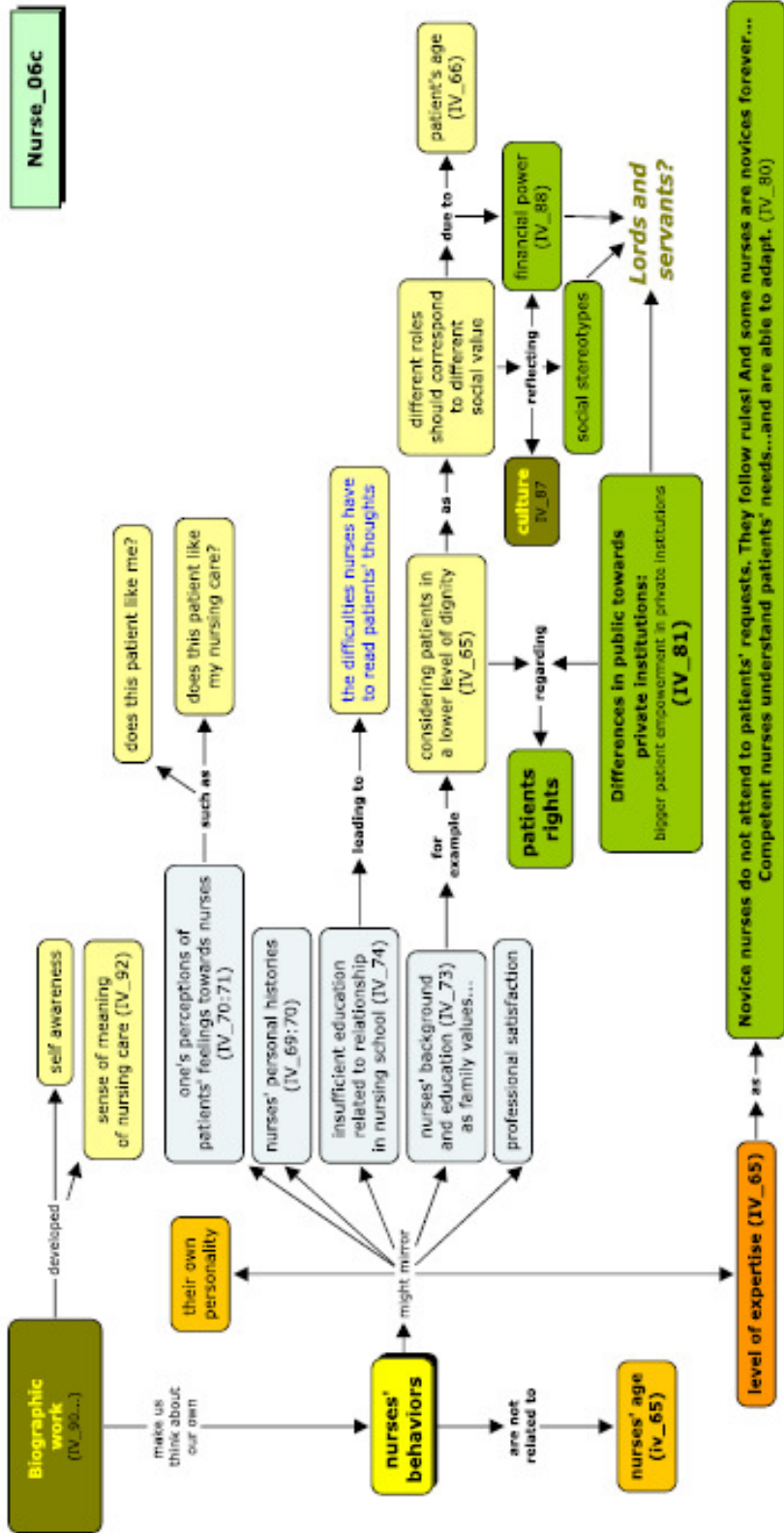
Nurse_04

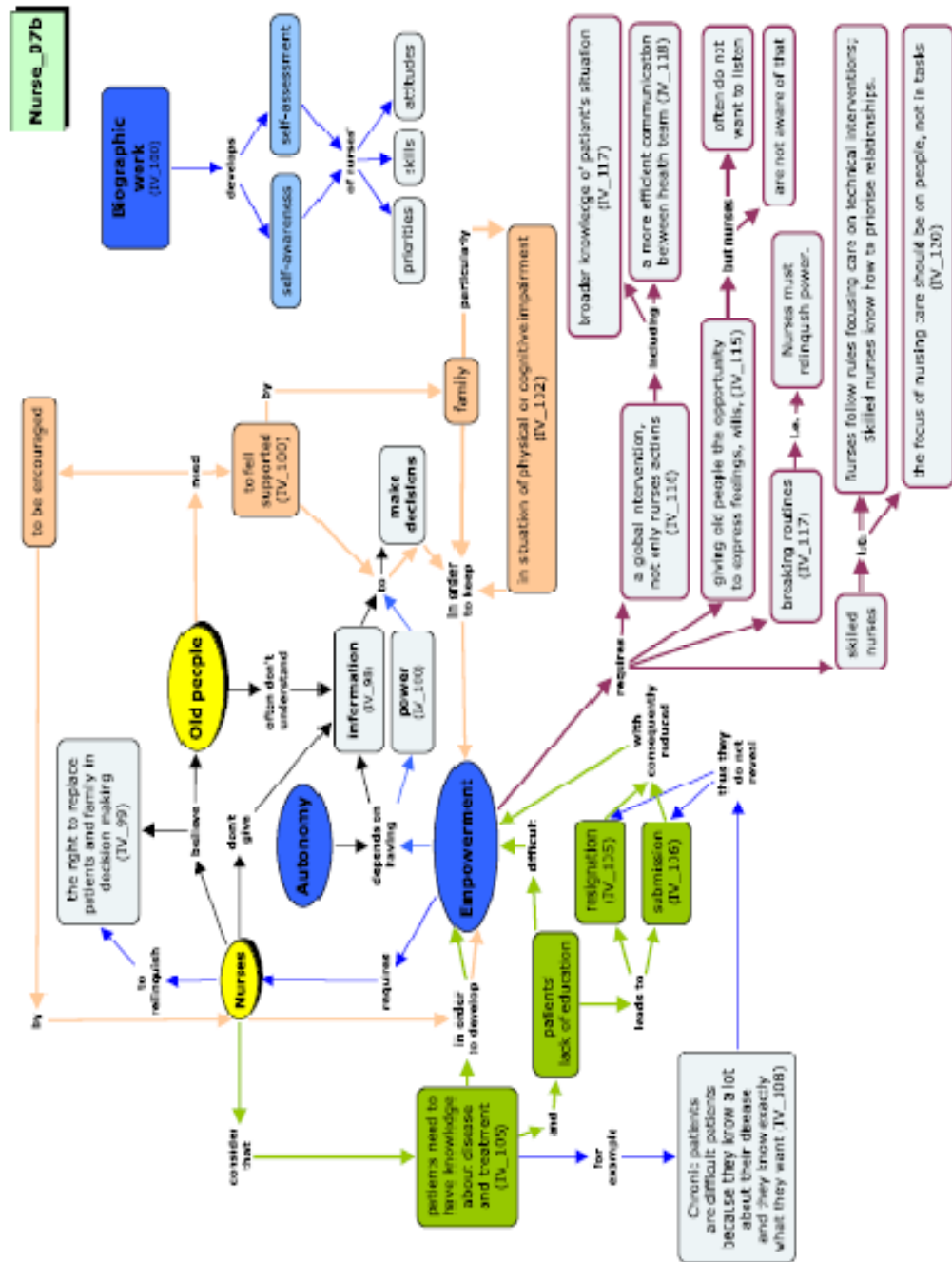


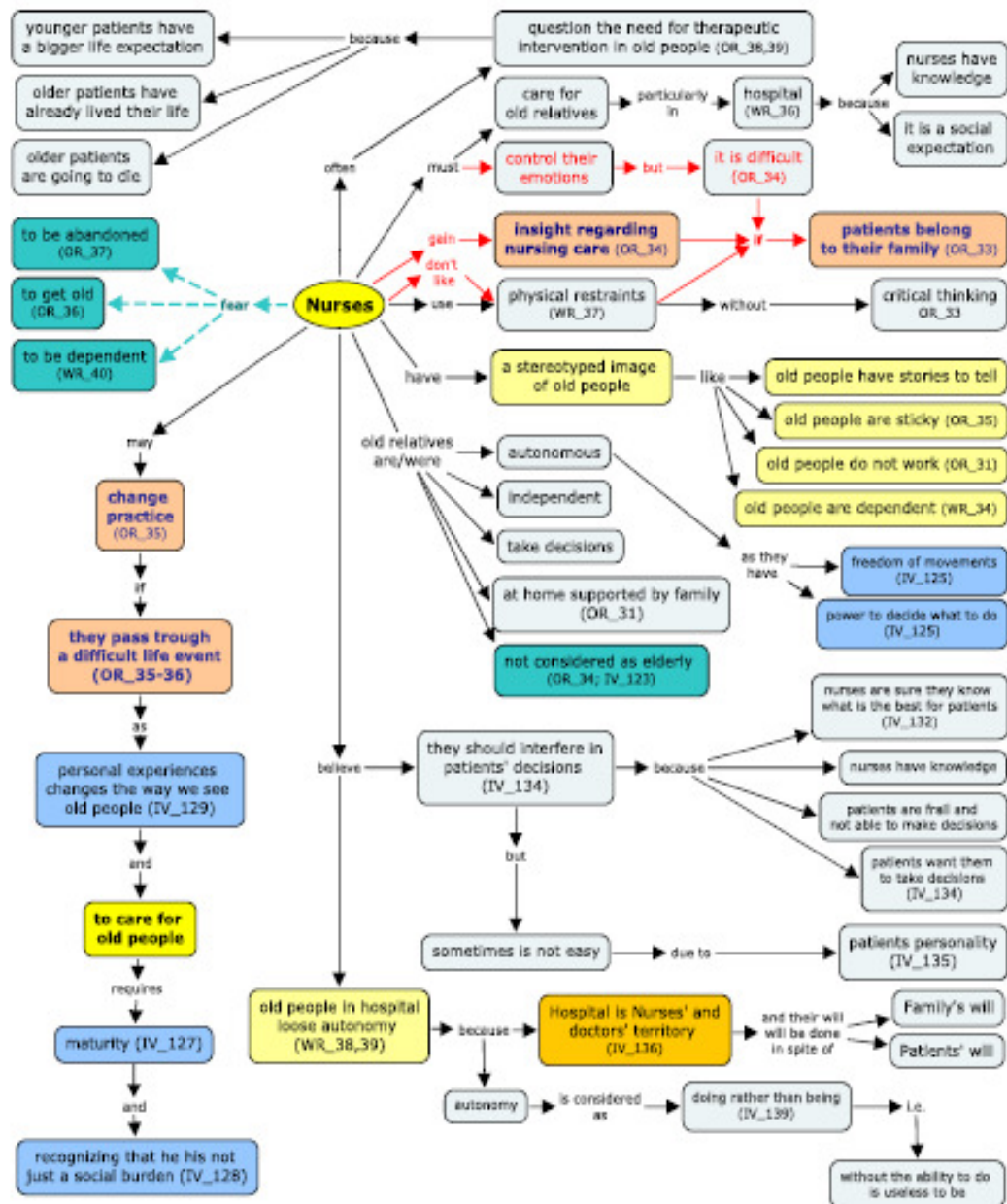


Nurse_06b

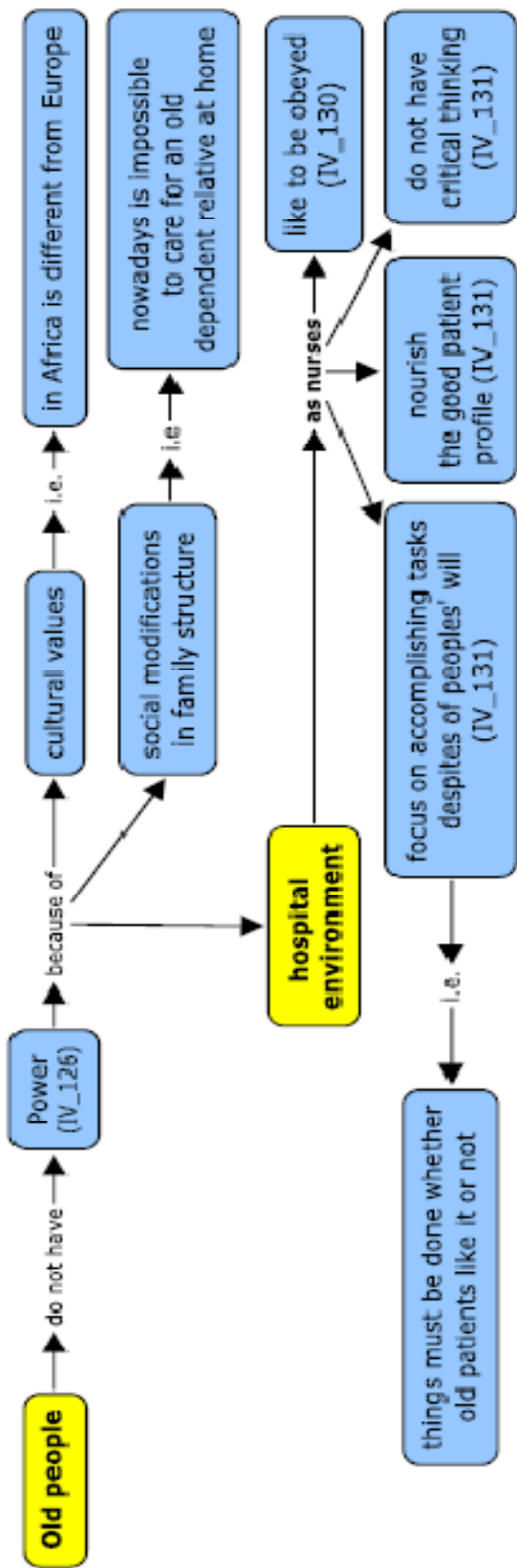




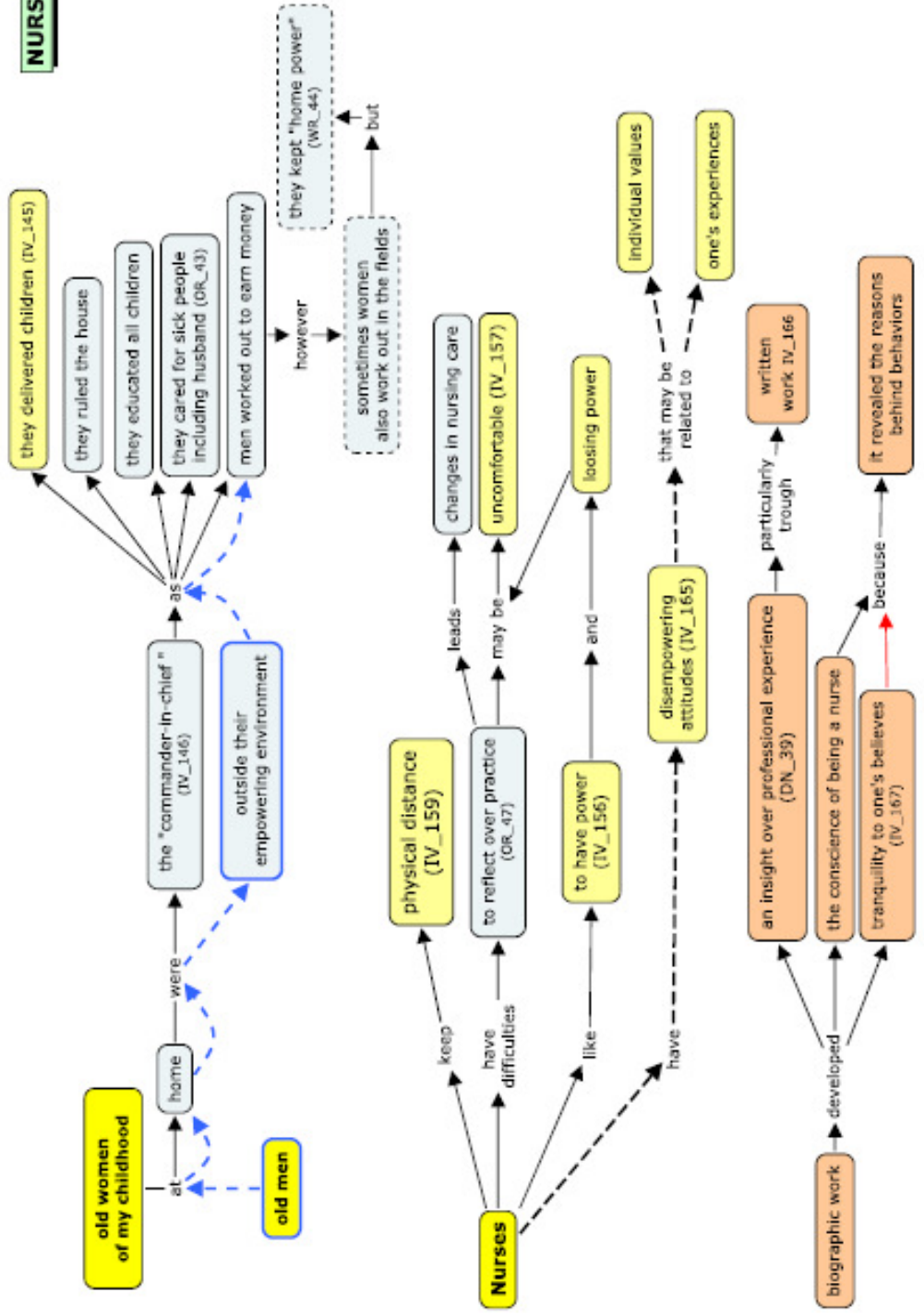




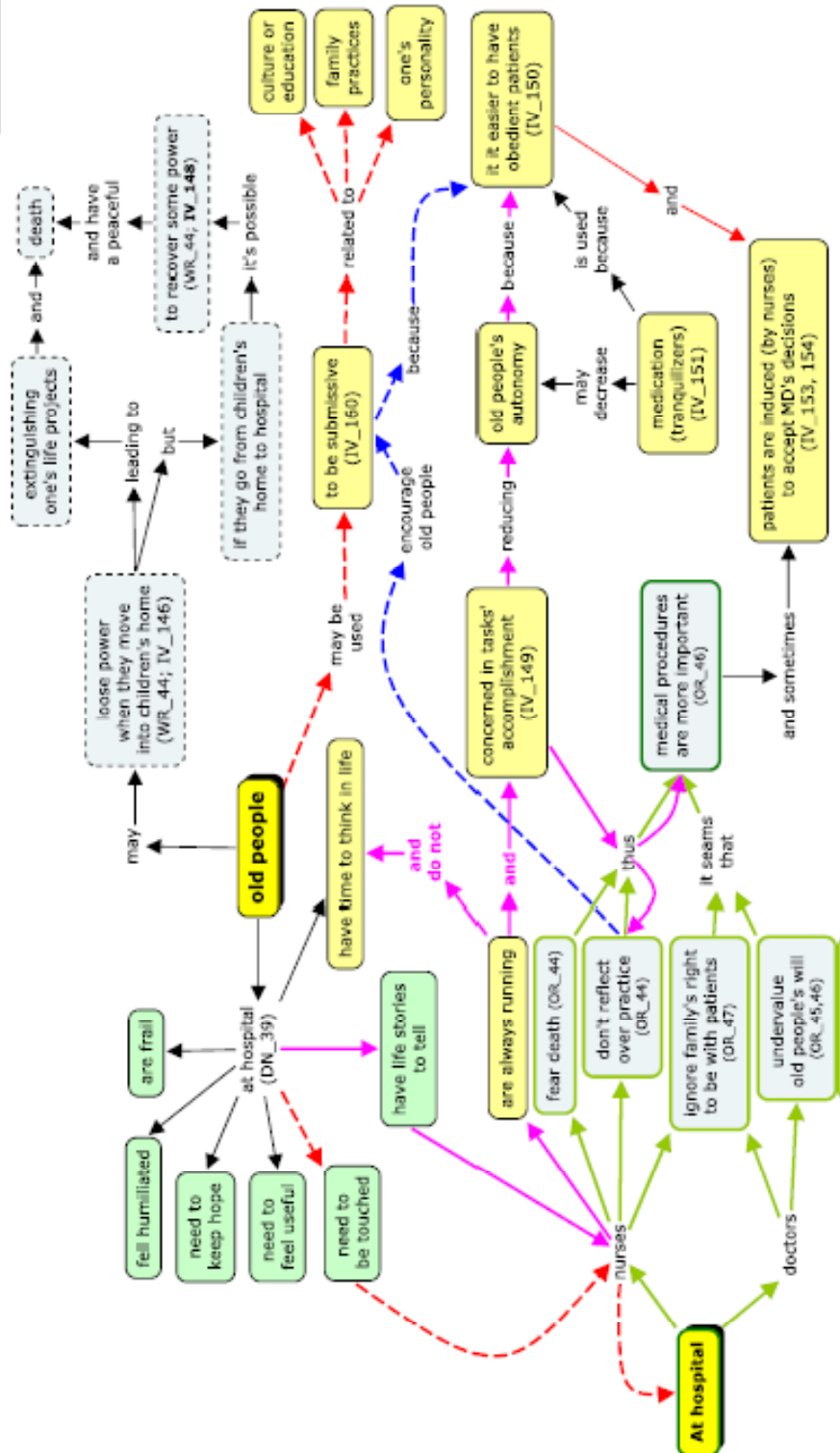
NURSE_08b

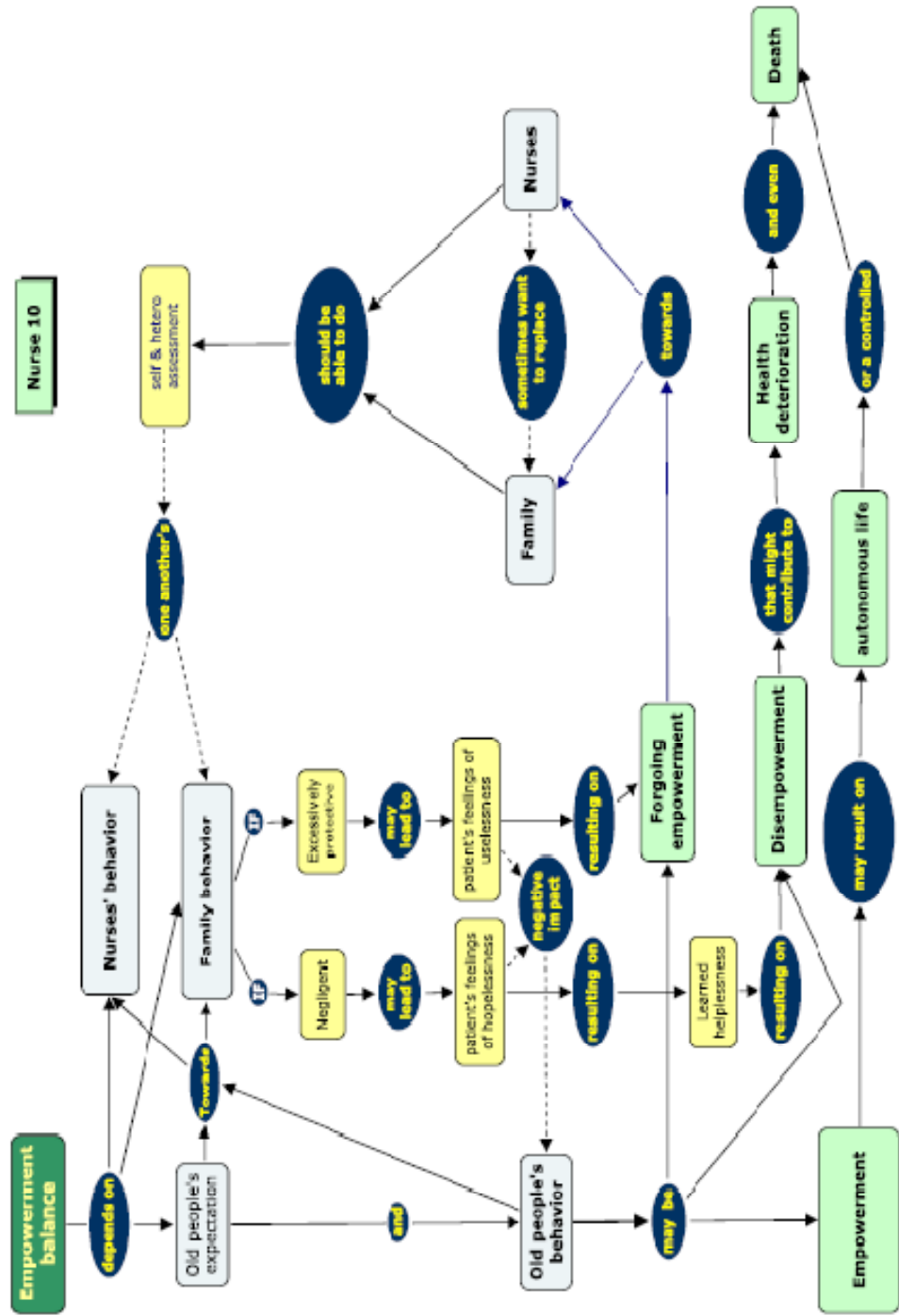


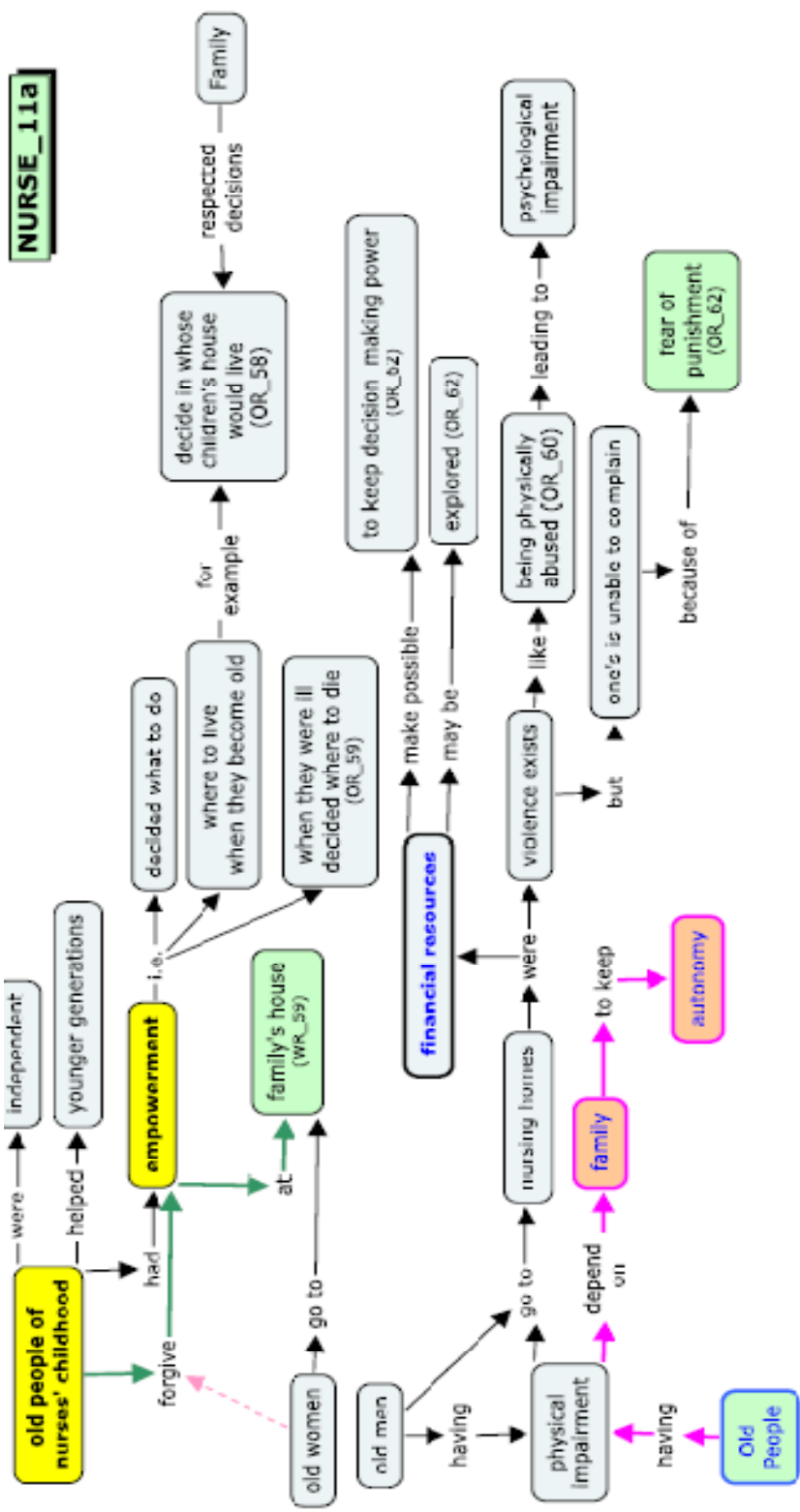
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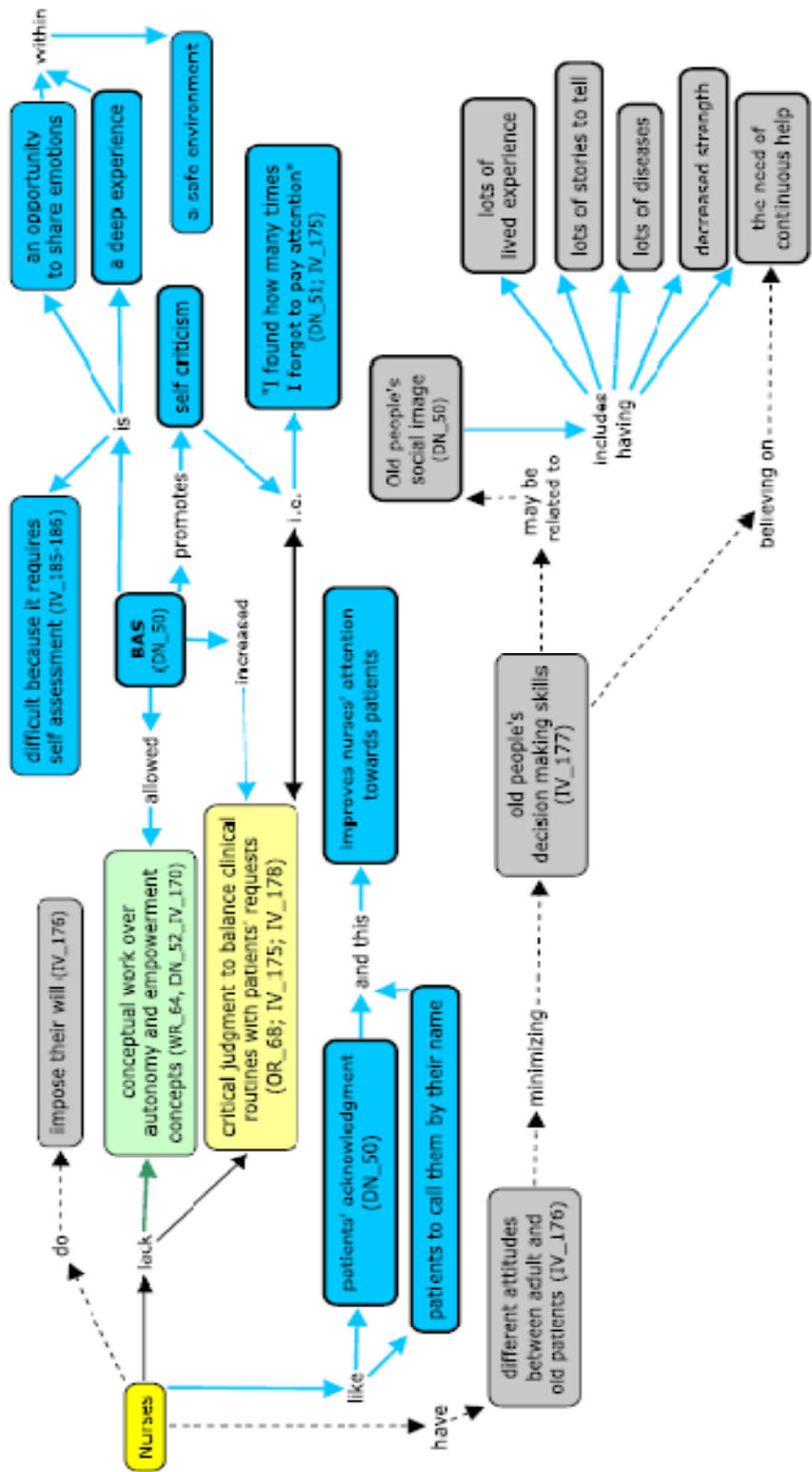
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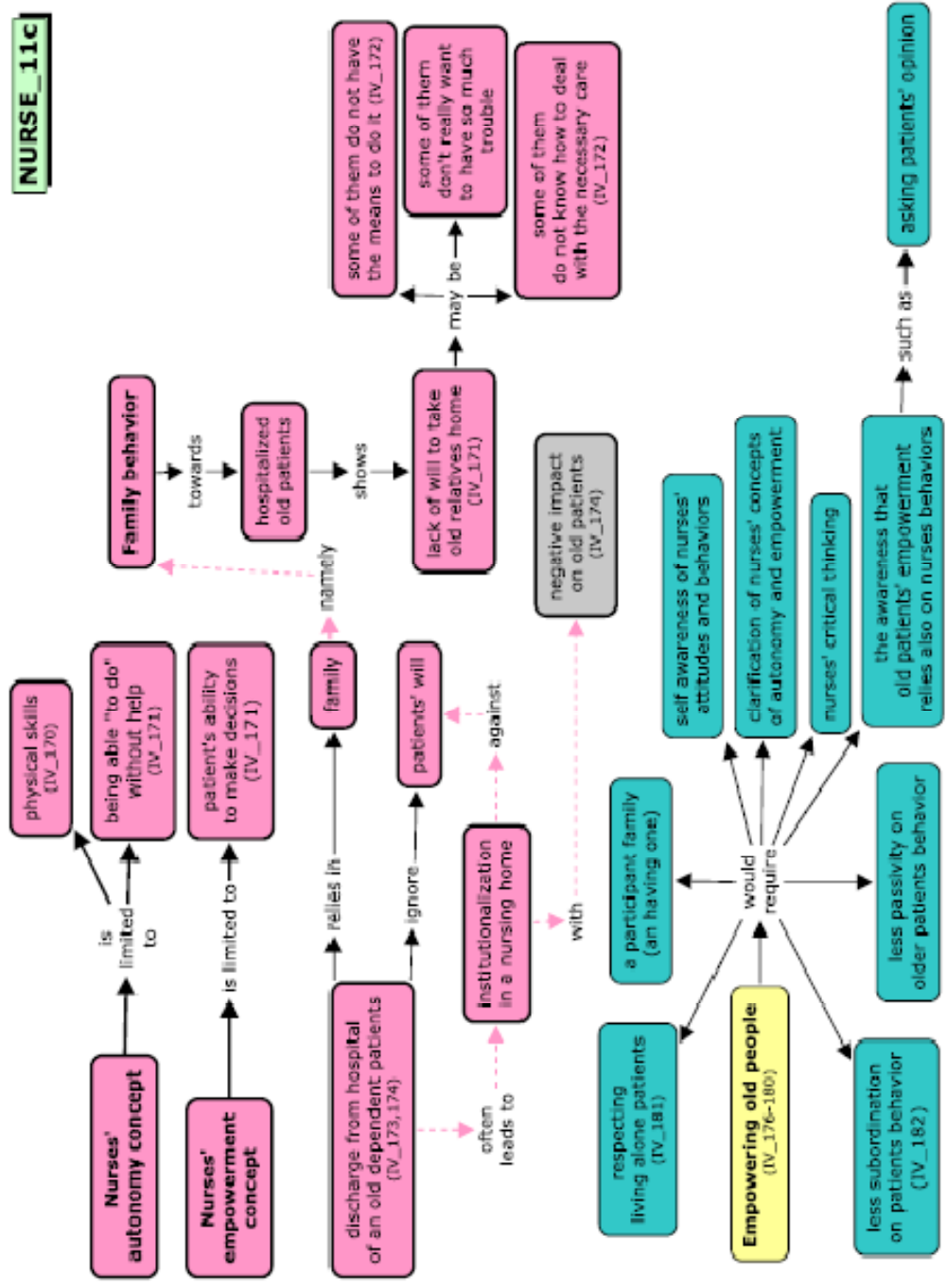




NURSE_11b

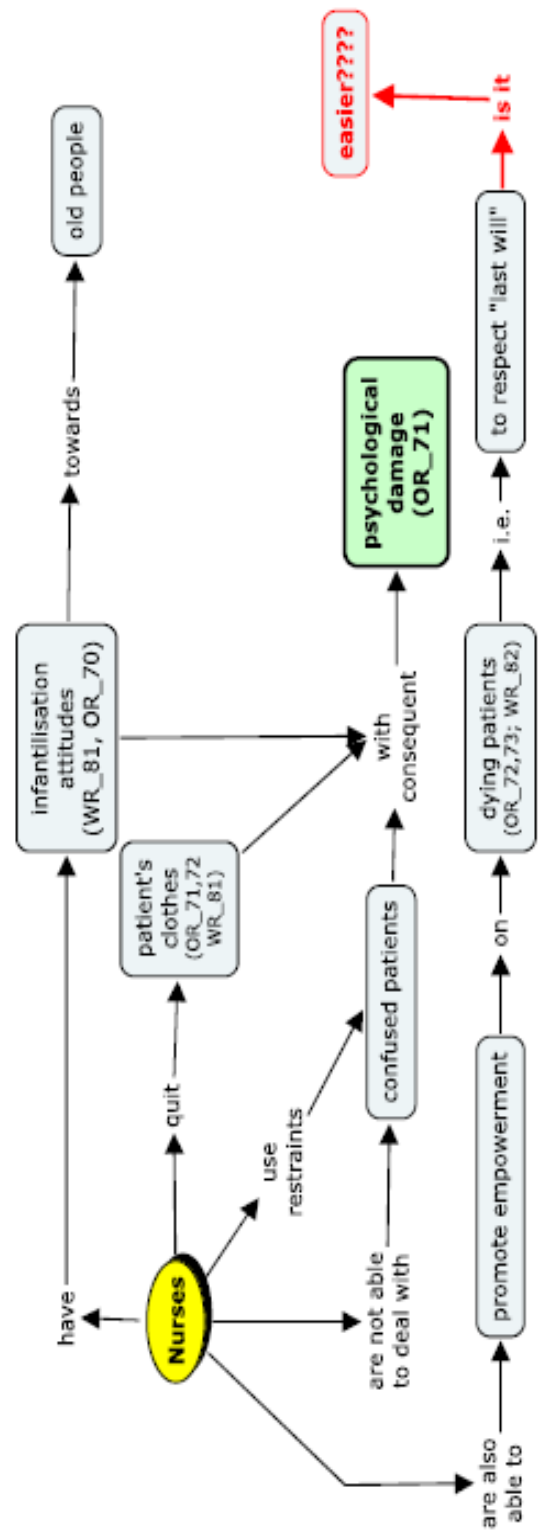
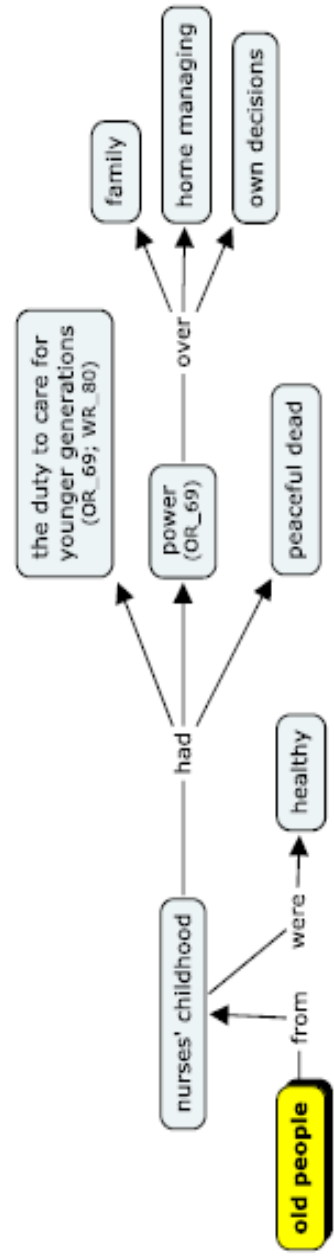


NURSE_11C

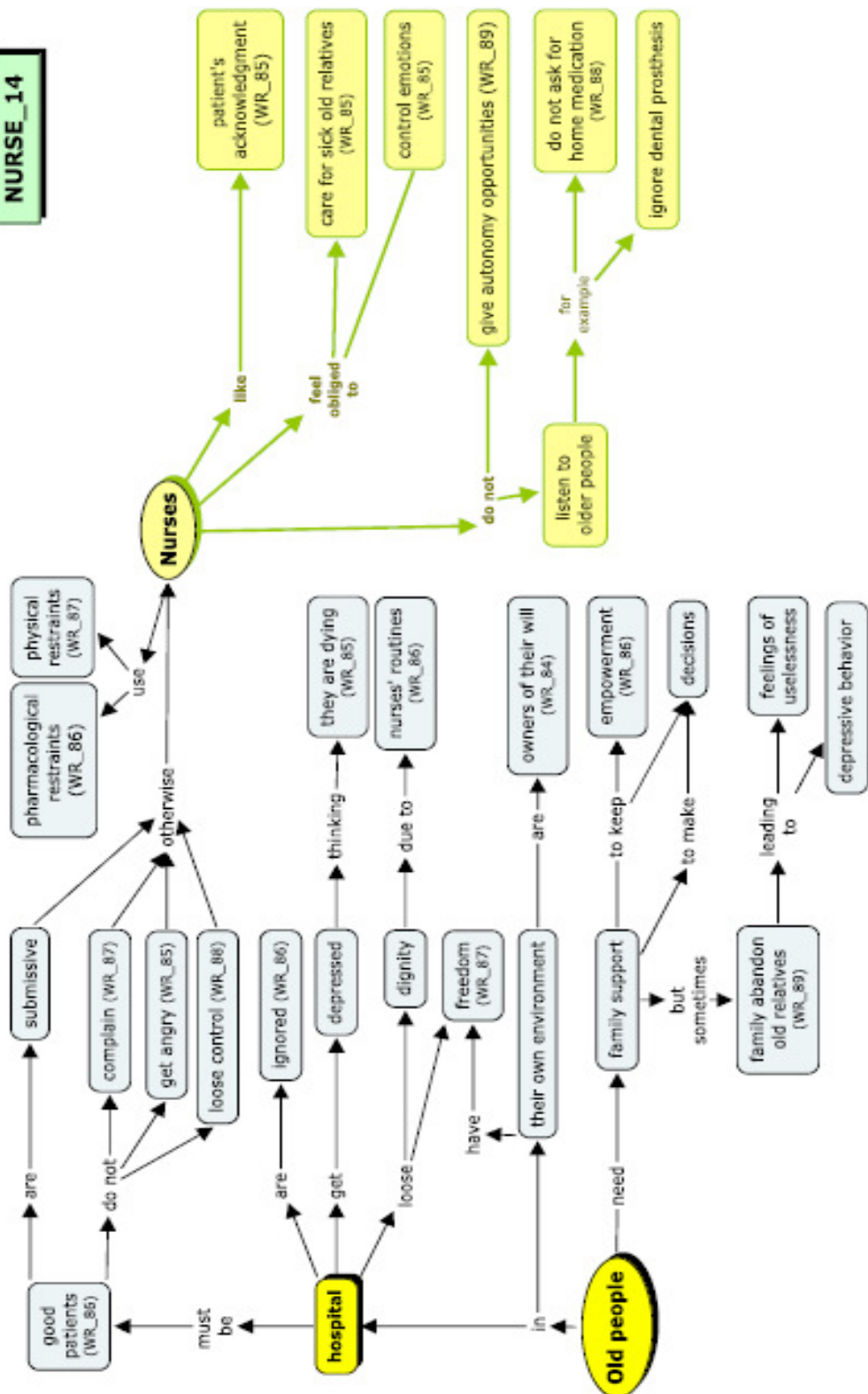




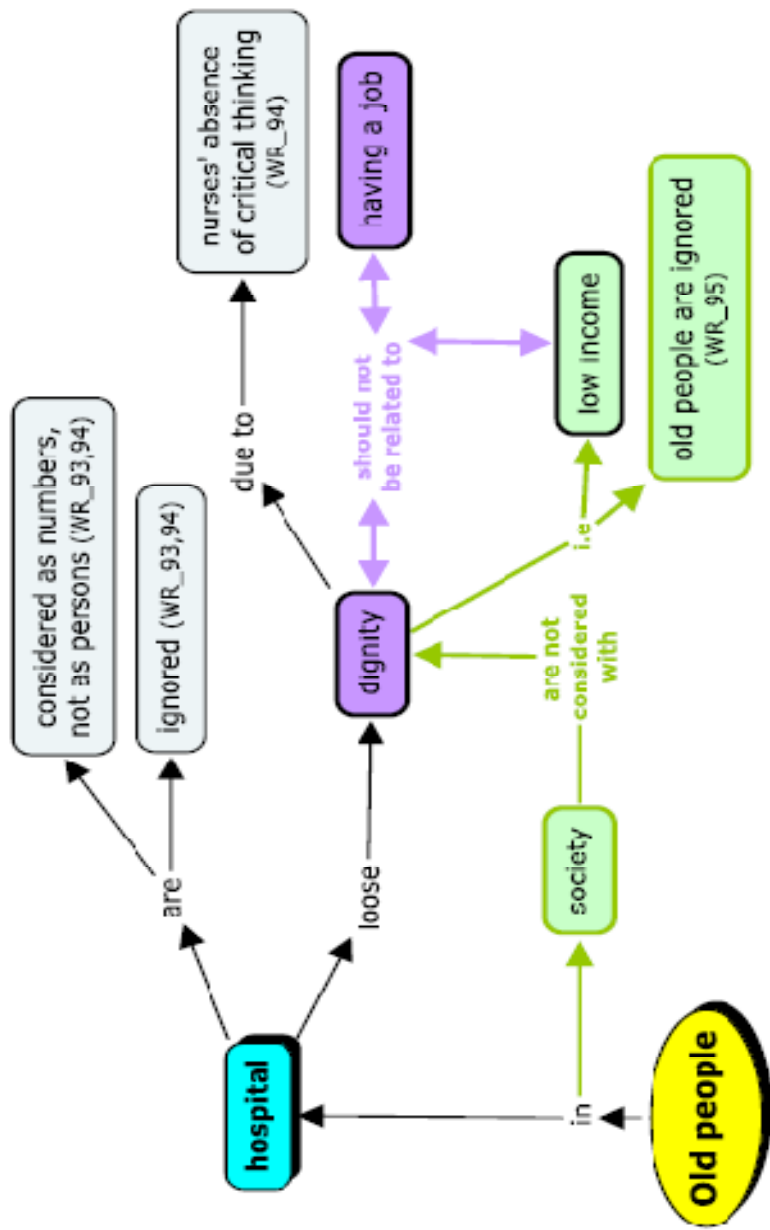
NURSE_13



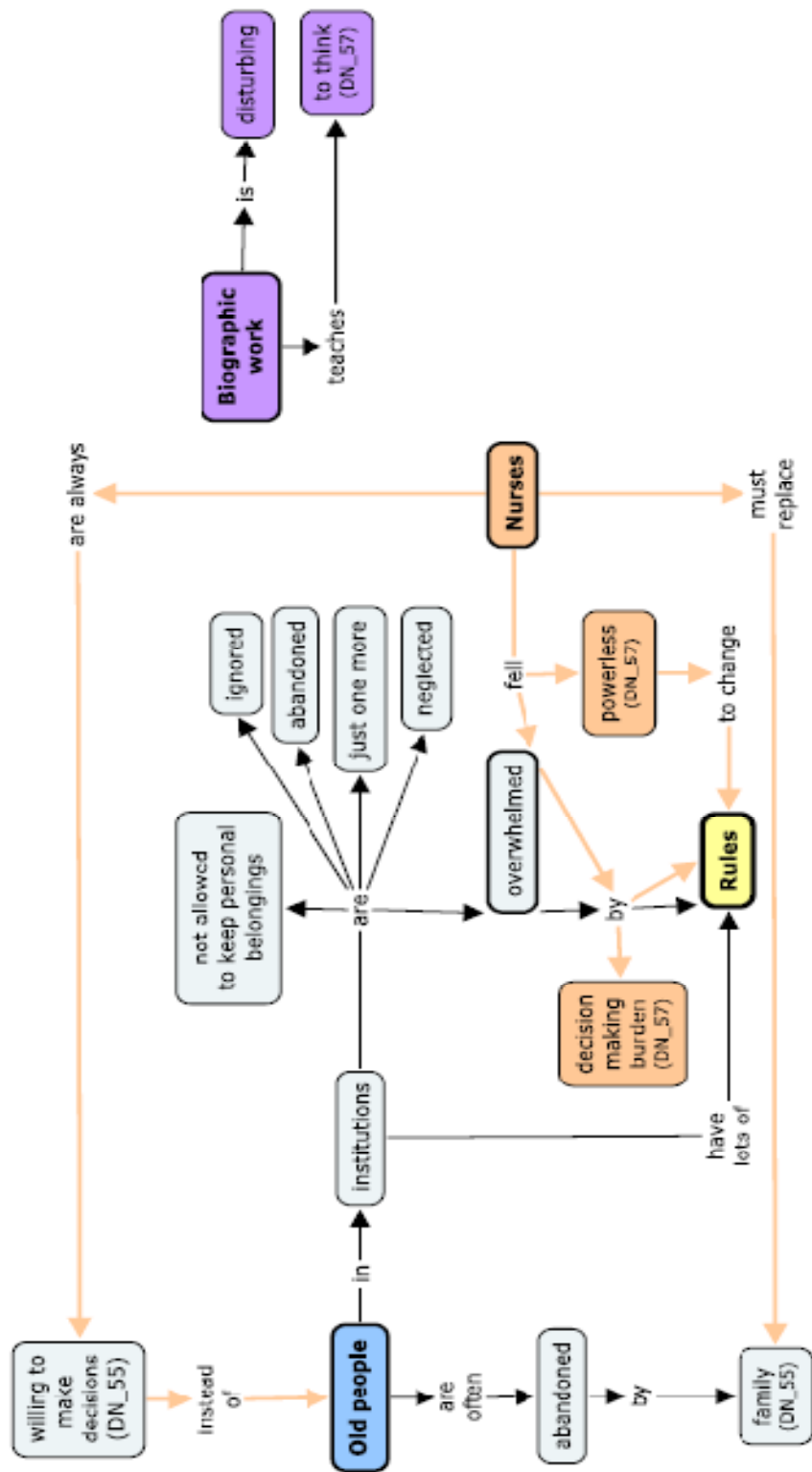
NURSE_14



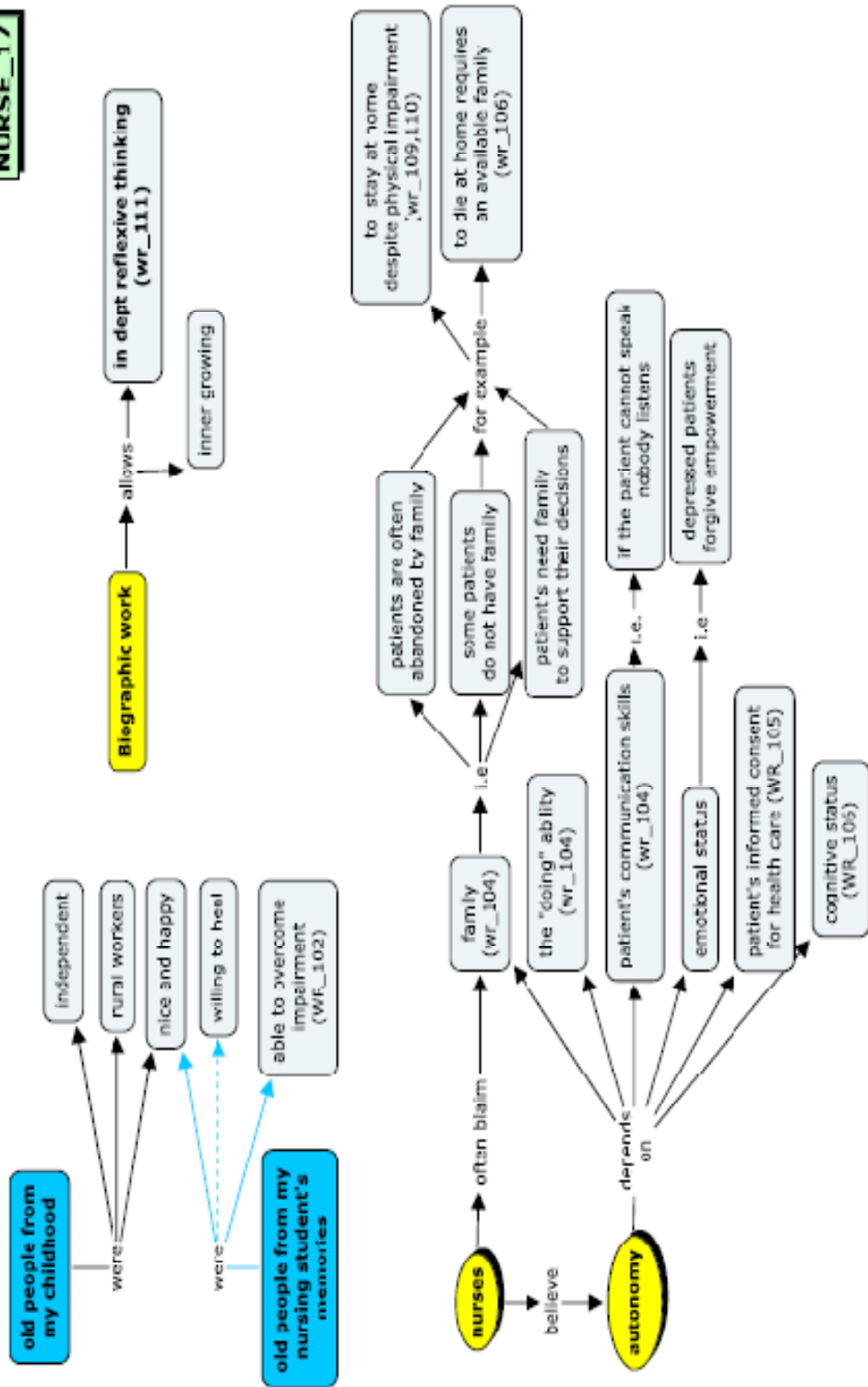
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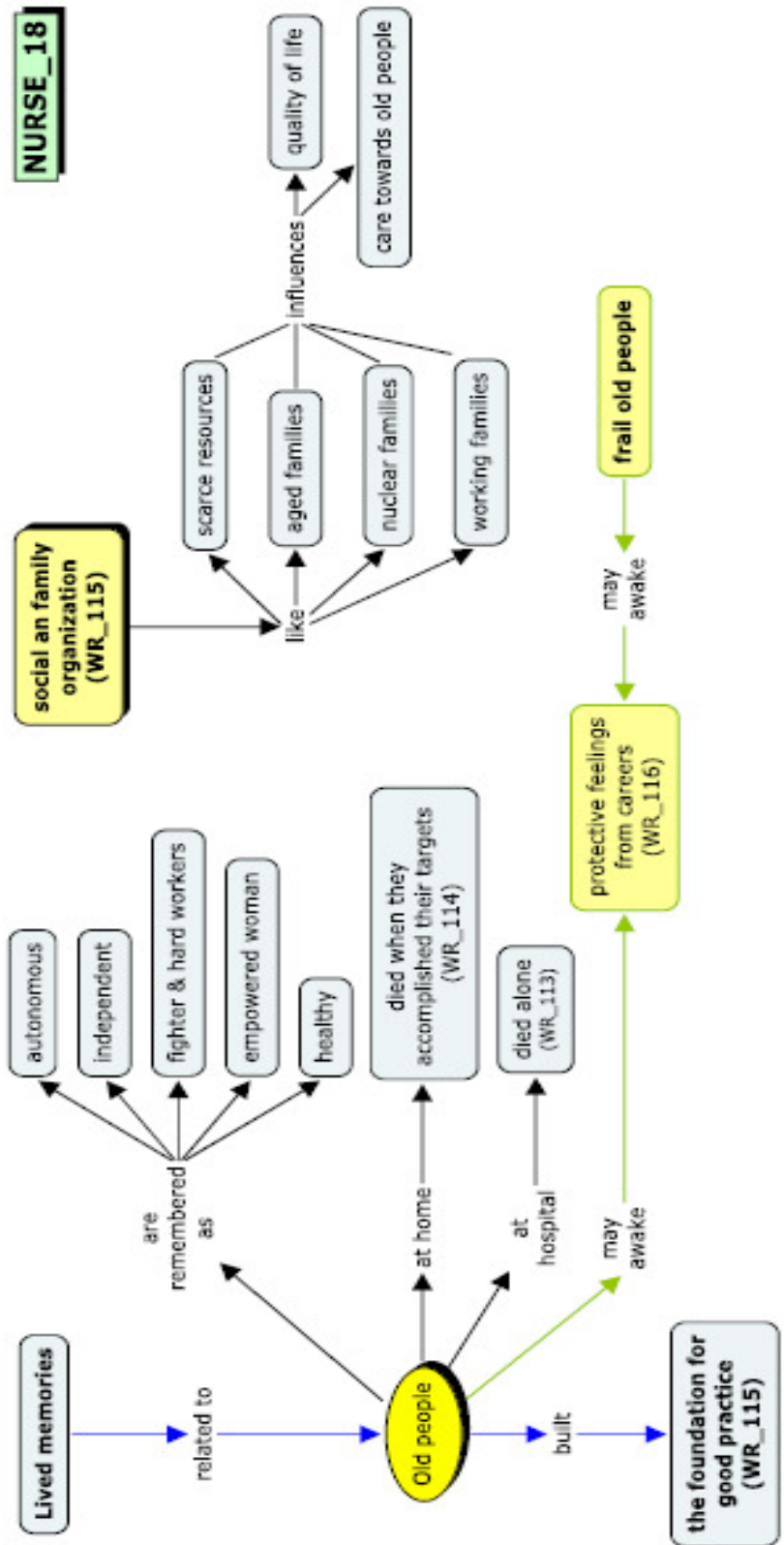


NURSE_16

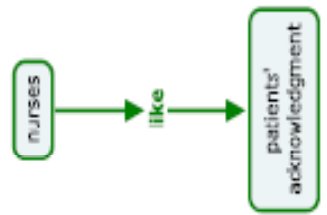
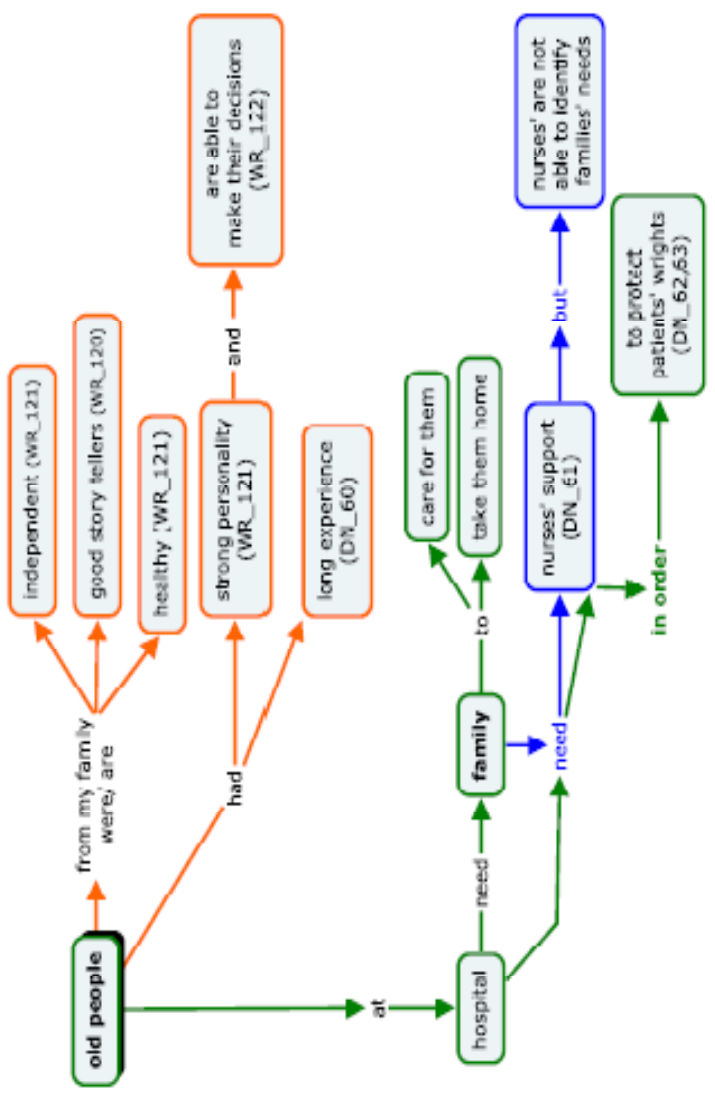
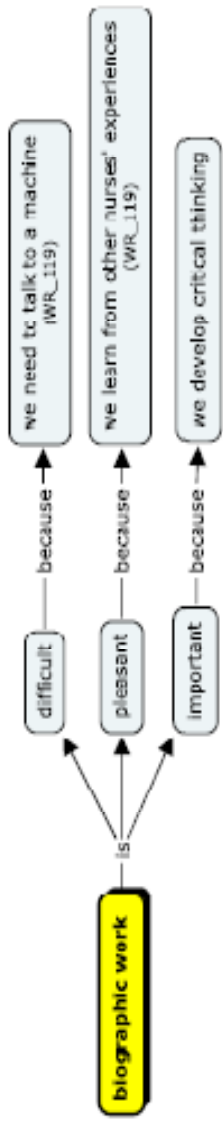


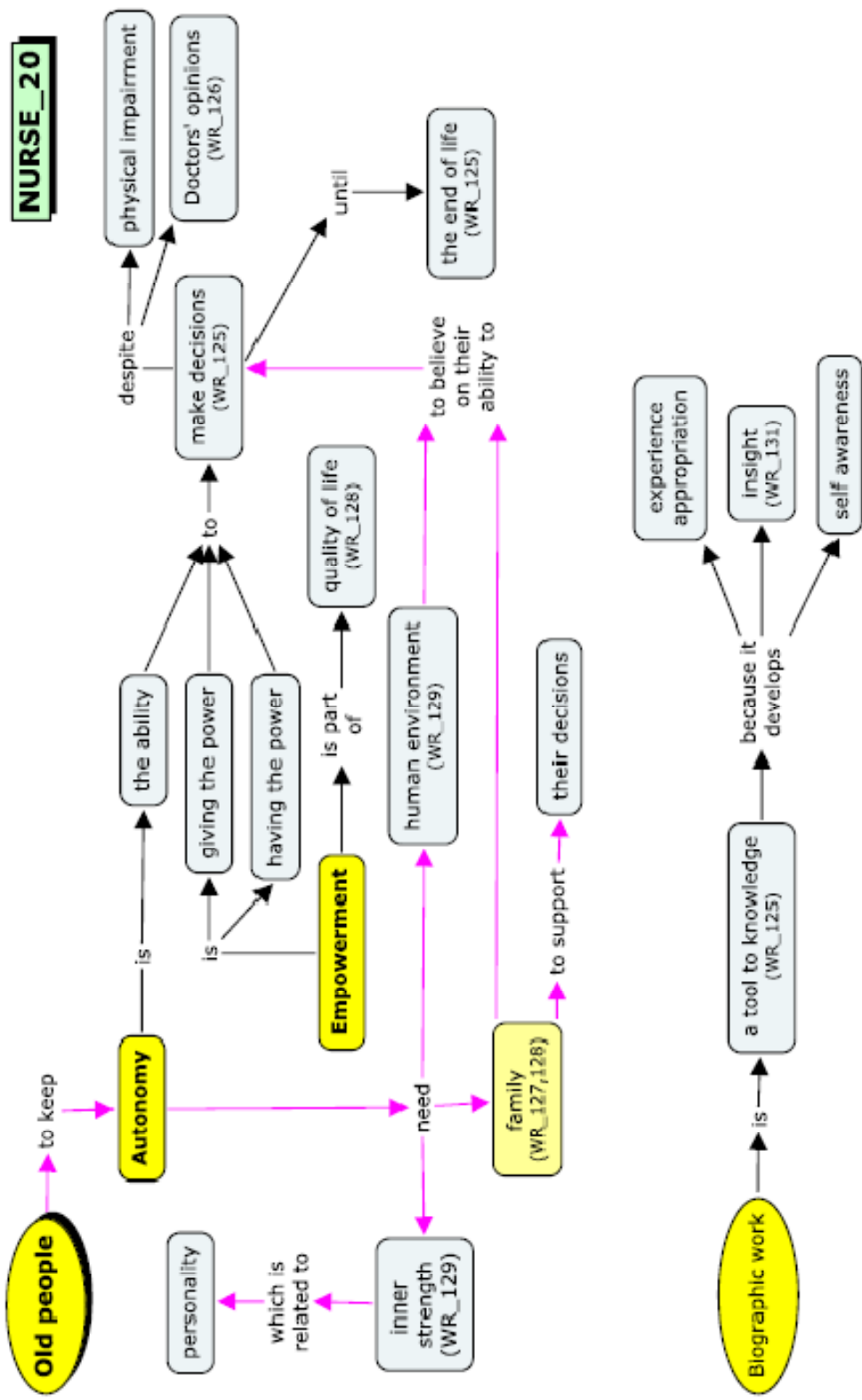
NURSE_17





NURSE_19





APPENDIX 20

NURSES' GLOBAL CONCEPTUAL MAP

Empowerment of hospitalized old people according to nurses' point of view is related to:

Older people

PERSONALITY

Inner strength
Passivity or submission versus fighting profile

COGNITIVE SKILLS

Communication skills
Cognitive impairment

EMOTIONAL STATUS

Depressed people forgive empowerment
Willing to heal

FUNCTIONAL STATUS

Independency in ADL's
Impaired old people depend on family to keep empowerment

Nurses'

BELIEFS

Empowering old people is difficult because it requires
Crossing professional boundaries
Extra-work for nurses
Less passivity from patients
An engaged family
Self awareness from nurses
Nurses critical thinking
A respectful attitude towards old people
Considering old patients equally respectable then nurses

Family has the social obligation to take care of older people
Older people nowadays are different from the past
Empowerment is demanding
Nurses have the right to replace family in decision-making
Patients do not have biomedical knowledge (essential for decision-making, in illness situations)

PRACTICES

Acting without thinking

Following rules

Keeping control

Over patients

Over situations

To use restrains

Nurses are focused on tasks accomplishment

ATTITUDES

To impose hospital rules, even if nurses do not agree with it

Nurses are always willing to make decisions

Nurses like to be obeyed

Nurses like patients acknowledgement

Nurses like to have power

IMAGE OF OLDER PEOPLE

Based on myths and stereotypes

Medical care consumers

Sad and lonely

Powerless

Social en family burden

Chronic patients

Built during childhood

Old people were independent

Old people were good story tellers

Old people were healthy

Old people had a strong personality

Old people had a long experience of life

Old people were always the decision- makers

Old people at hospital died alone

Old people were hard workers

Old people cared for the younger generations

Old people in hospital are different from the ones from nurses' childhood memories

NURSING EDUCATION

Nurses have the knowledge

Nurses must make decisions

Old people's family

MUST BE SUPPORTIVE

To answer to patients' physical needs

To make old relatives decisions be respected

MUST BE EVER PRESENT

MUST BE ALWAYS READY TO TAKE OLD RELATIVES HOME

ABANDON OLD PEOPLE IN HOSPITAL OR NURSING HOMES

Old people become sad and depressive

Old people are abused or suffer violence

DO NOT KNOW HOW TO CARE FOR SICK OLD PEOPLE

SOMETIMES IS EXCESSIVELY PROTECTIVE

Hospital

PHILOSOPHY AND CULTURE

In hospital there is no place for personal belongings

In hospital patients are statistics and figures

Bed number

Procedure number

Hospitalization number

Surgery number

Mortality rate

The good patient profile is encouraged

Do not complain

Do not get angry

Do not loose cognitive or emotional control

Is submissive

Medical procedures are more important than patients' wishes

HUMAN ENVIRONMENT

There is a reduced number of nurses

MDs should be able to respect older people's will

**HOSPITAL PRACTICES' MIRROR SOCIAL (POOR) VALUE OF OLD
PEOPLE**

Society

FINANCIAL RESOURCES AVAILABILITY AND ALLOCATION

Old people have generally low income

Without financial independence it is impossible to keep decision making power

In private institutions patients have more power

CULTURAL VALUES

Old people are considered as a social burden

African societies are more respectful of older people than European societies

FAMILY STRUCTURE AND ORGANIZATION

Often old people do not have family

Contemporaneous families are different from past families

Families do not have time or facilities to care for old people

Gender

WOMEN

Cared for children and sick people

Know how to care

Decided what patients may do or not

Had power at home

Decided rules

Cared for the ill

Educated all (male and female)

When they widowed

Had the power to decide for their lives

Usually stay at one's house

MEN

Had power outside house, in jobs

Represent the family (for legal issues)

When they are ill, they depend on women

When they became widows

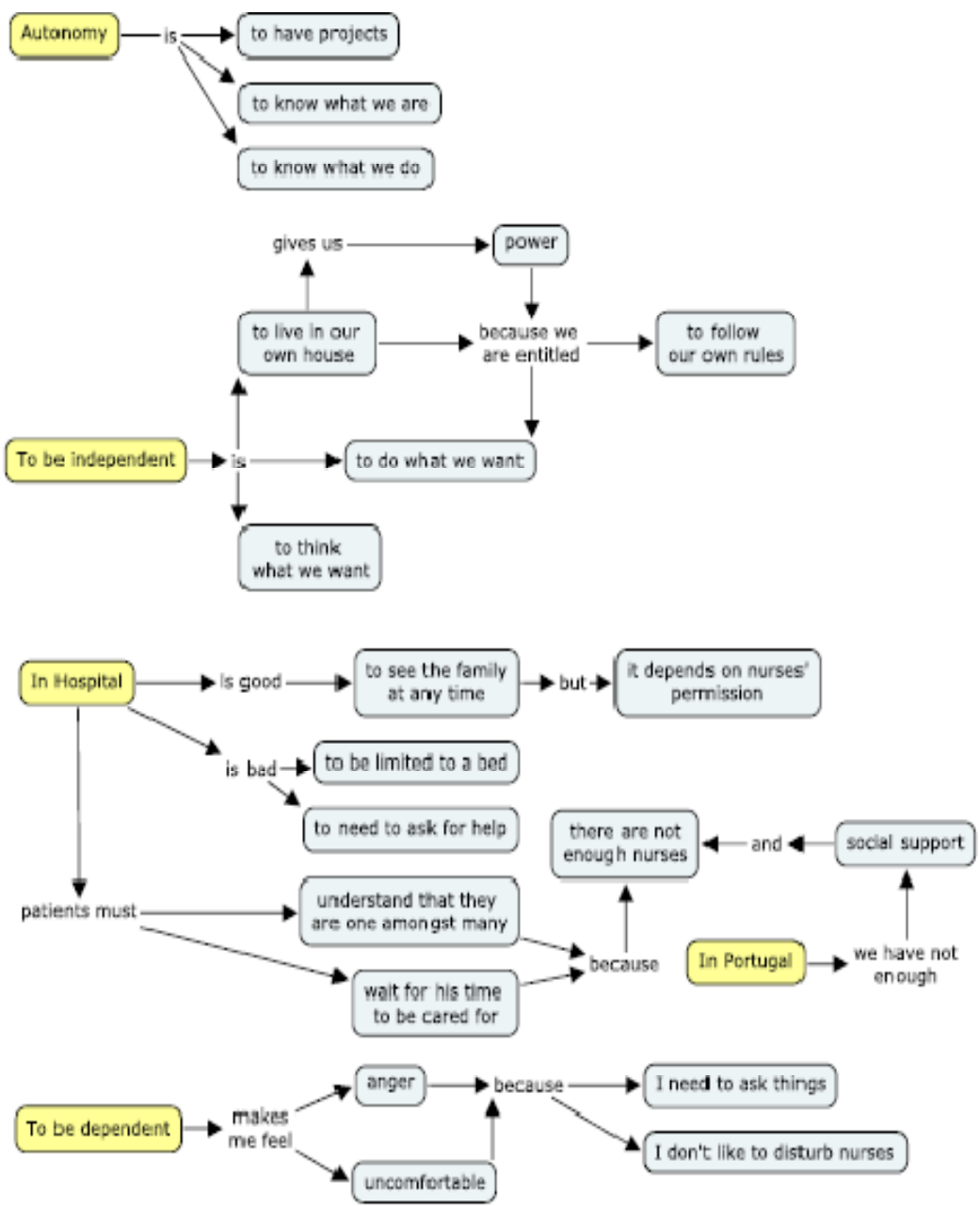
Went to children's house or get married again

If they have physical impairment are placed into nursing homes

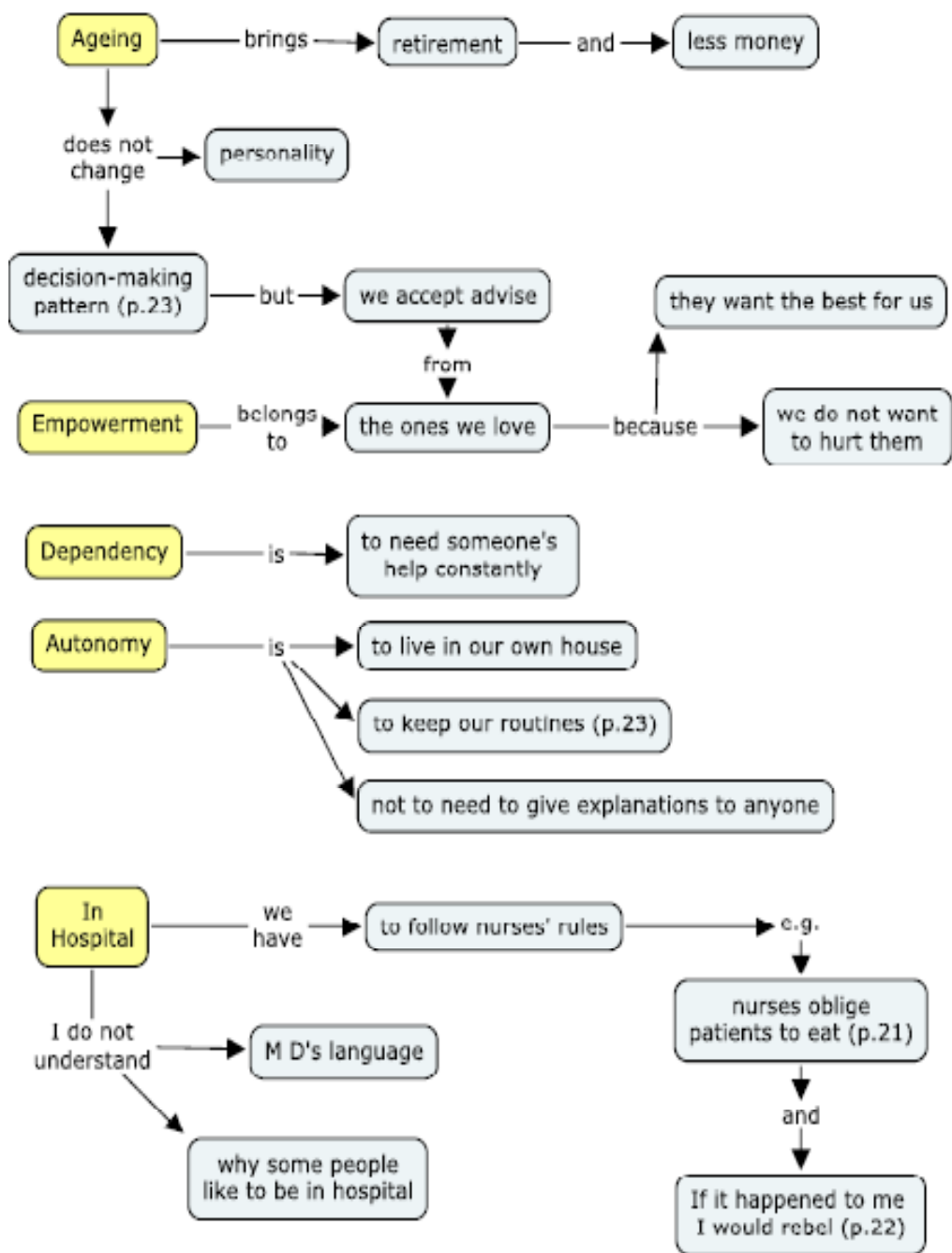
APPENDIX 21

PATIENTS' CONCEPTUAL MAPS

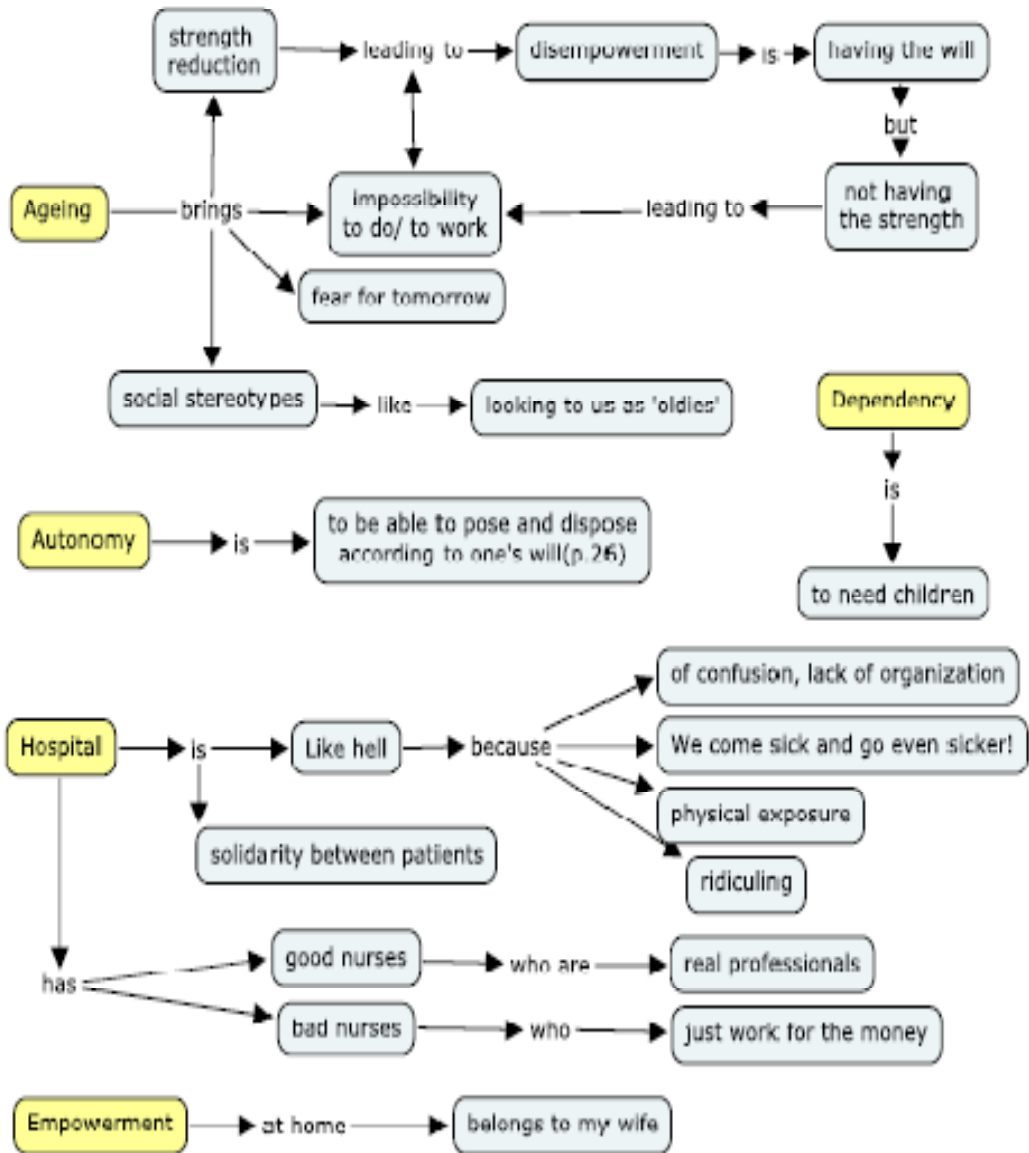
Patient_01

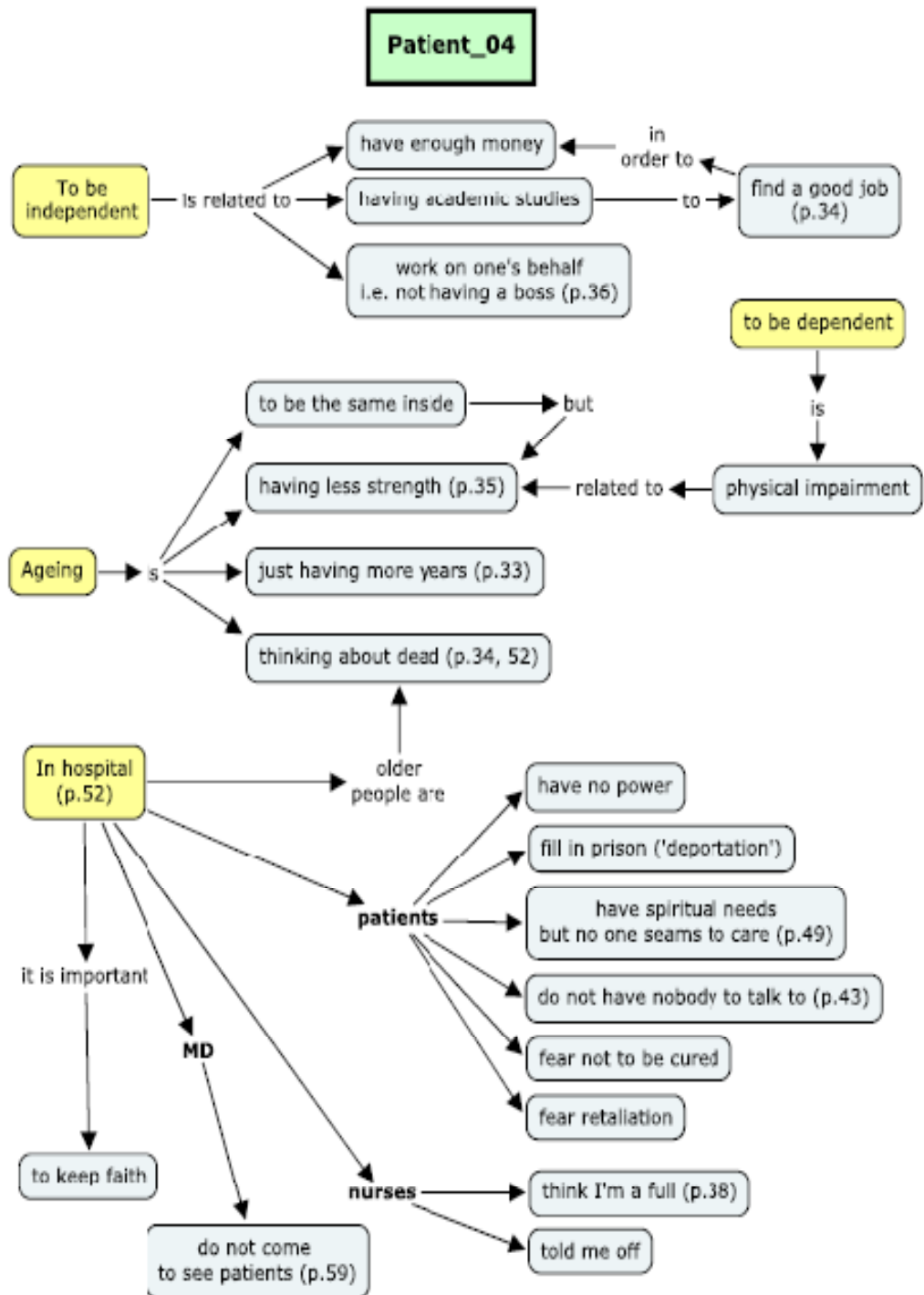


Patient_02

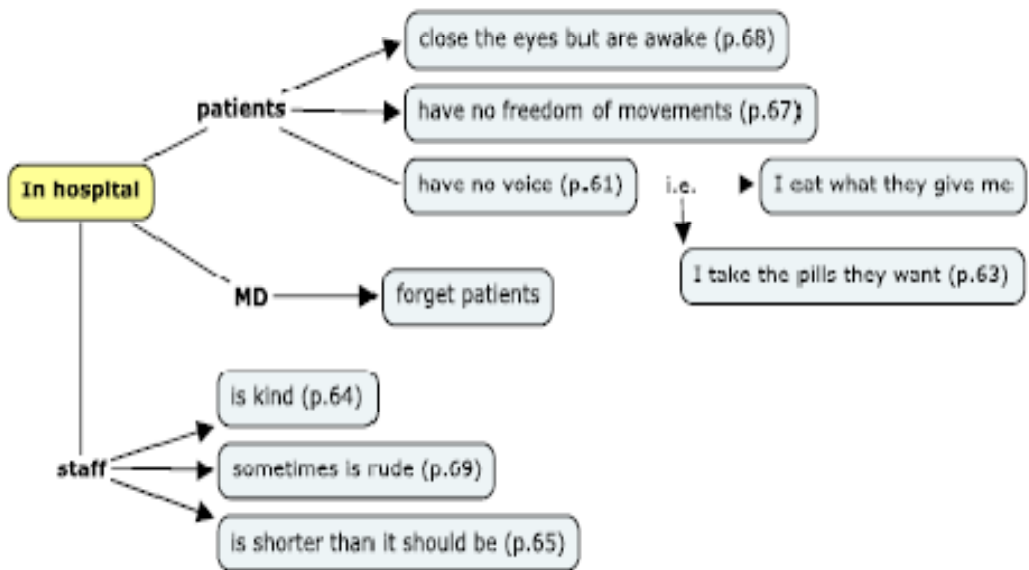
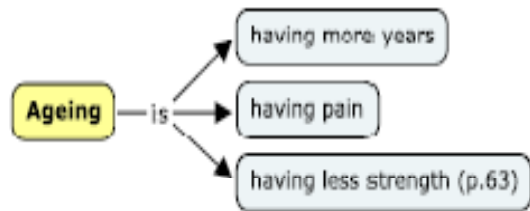


Patient_03

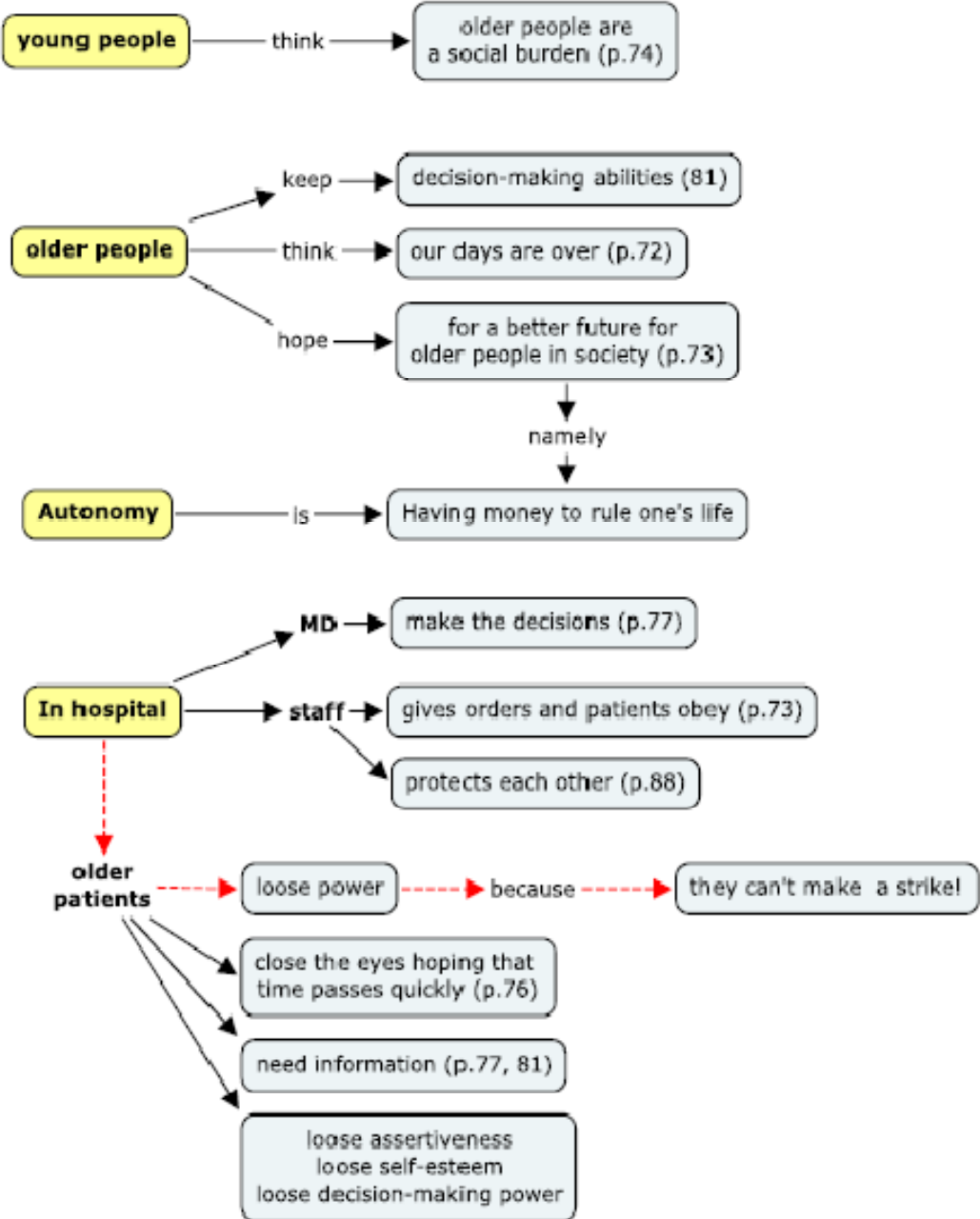




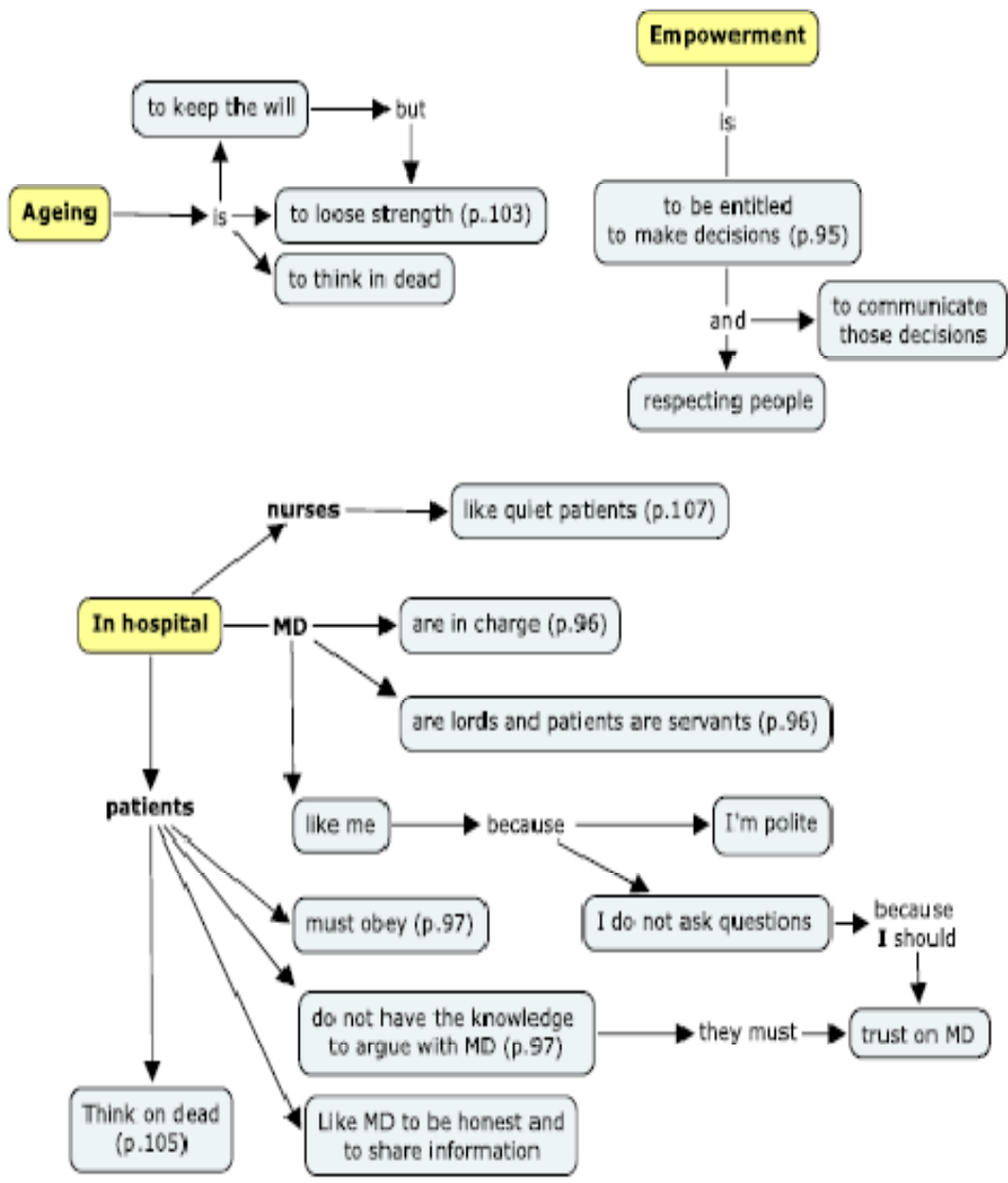
Patient_05



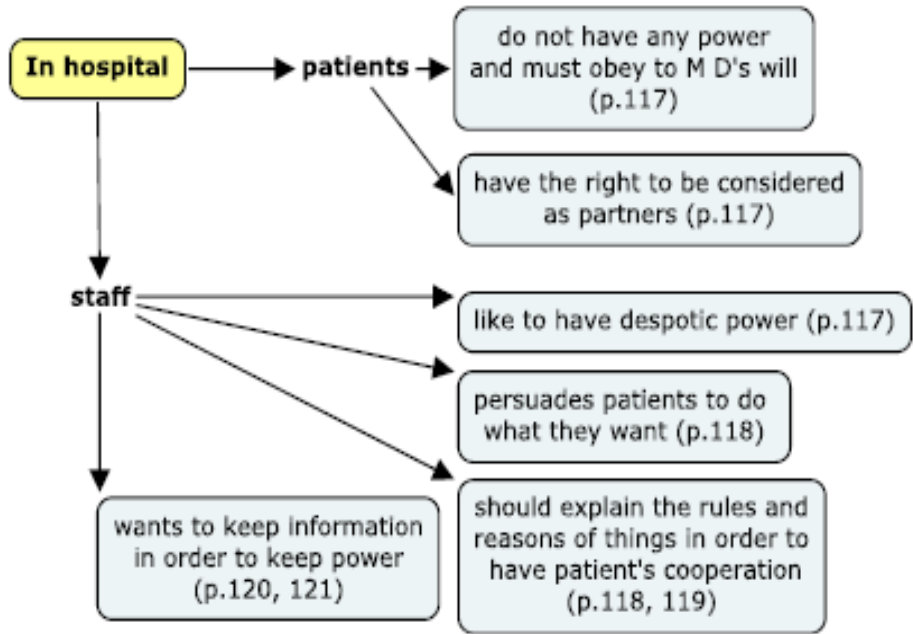
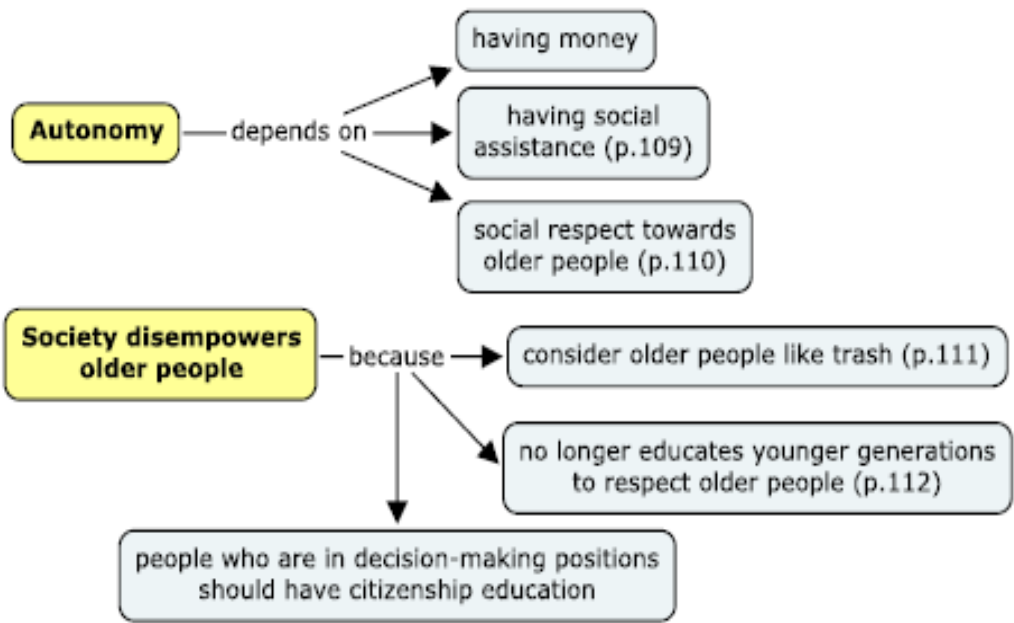
Patient_06



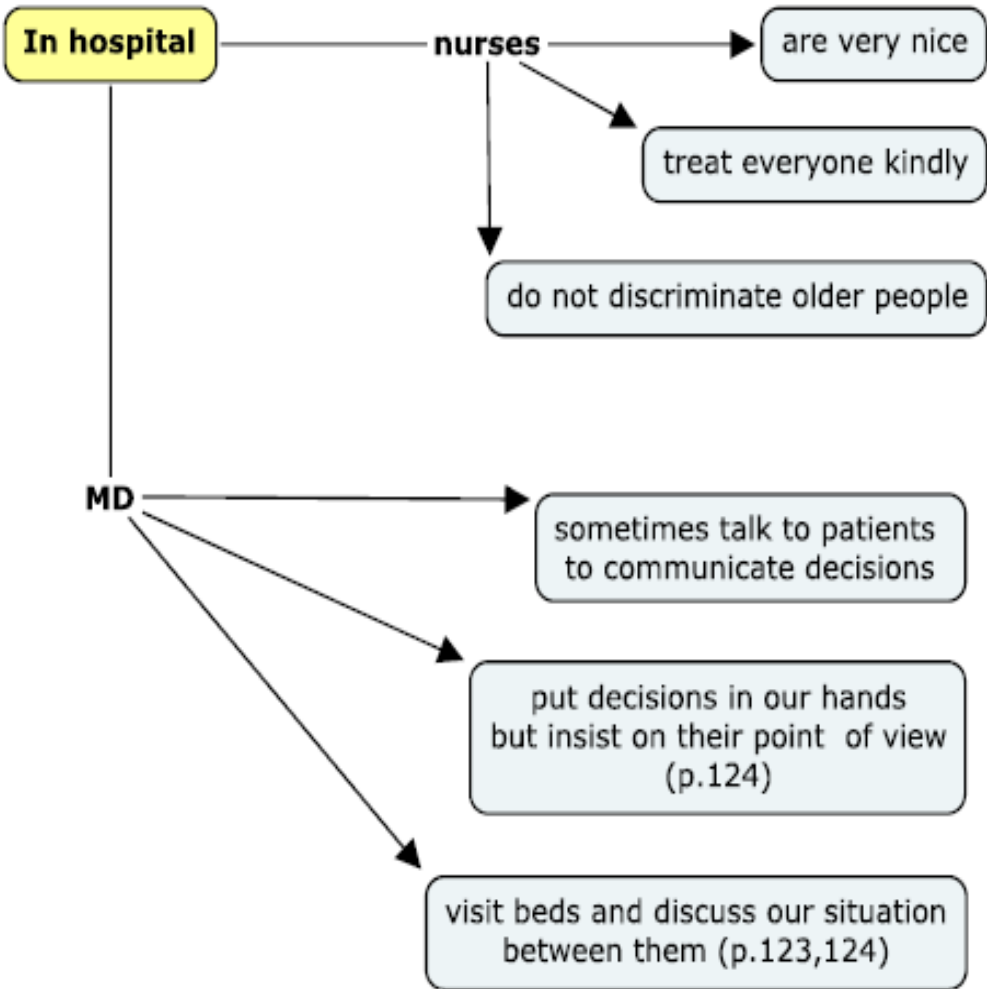
Patient_07



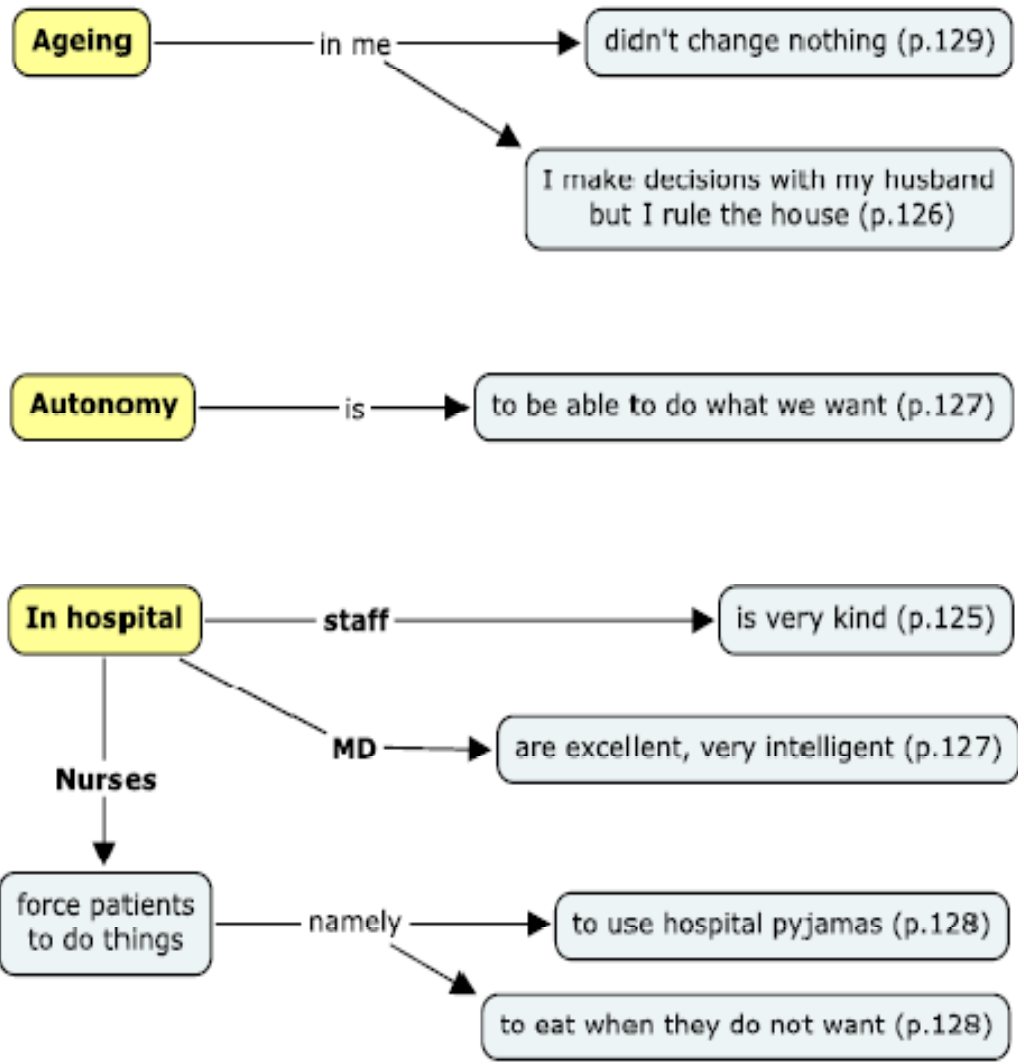
Patient_08

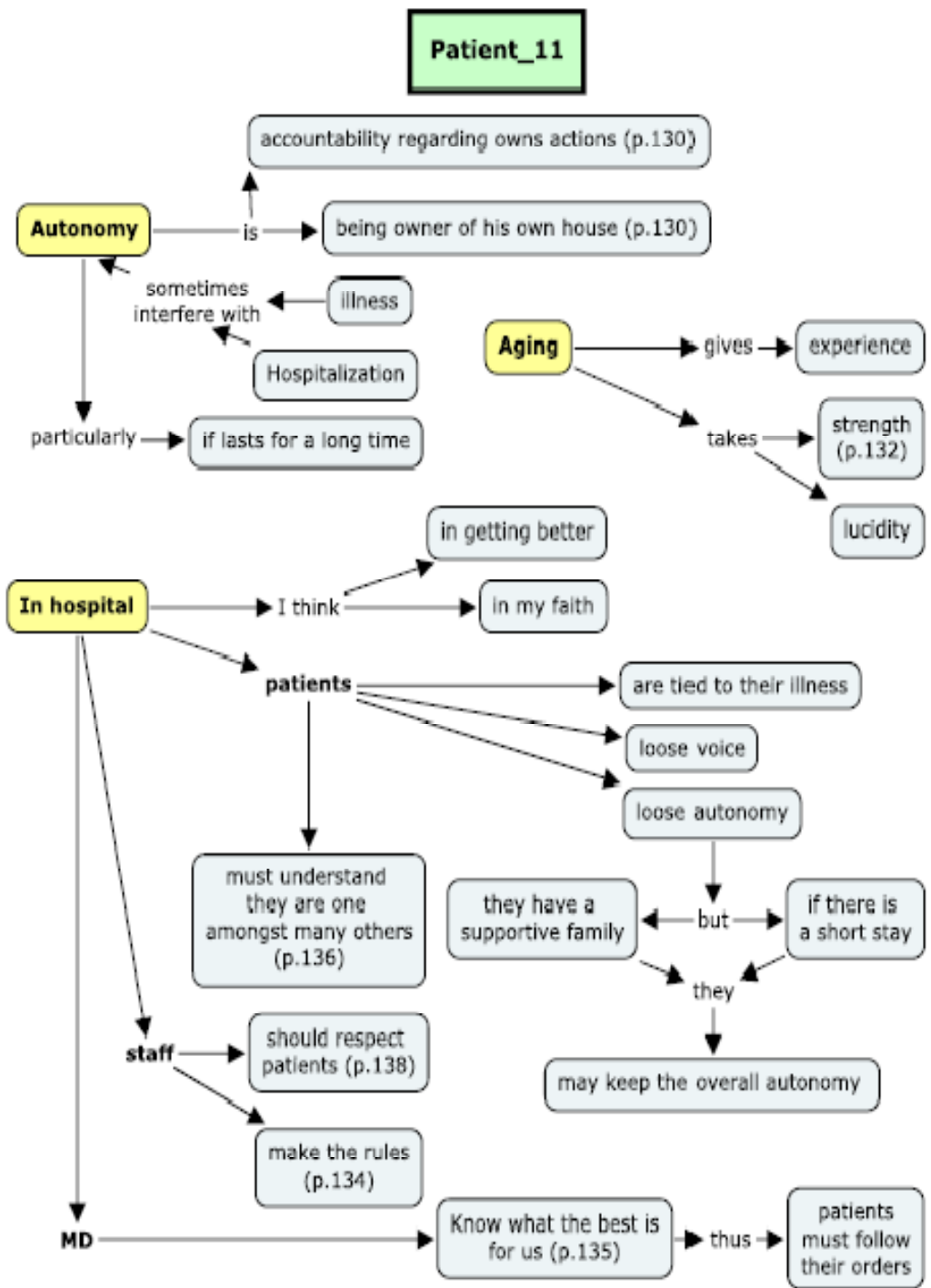


Patient_09

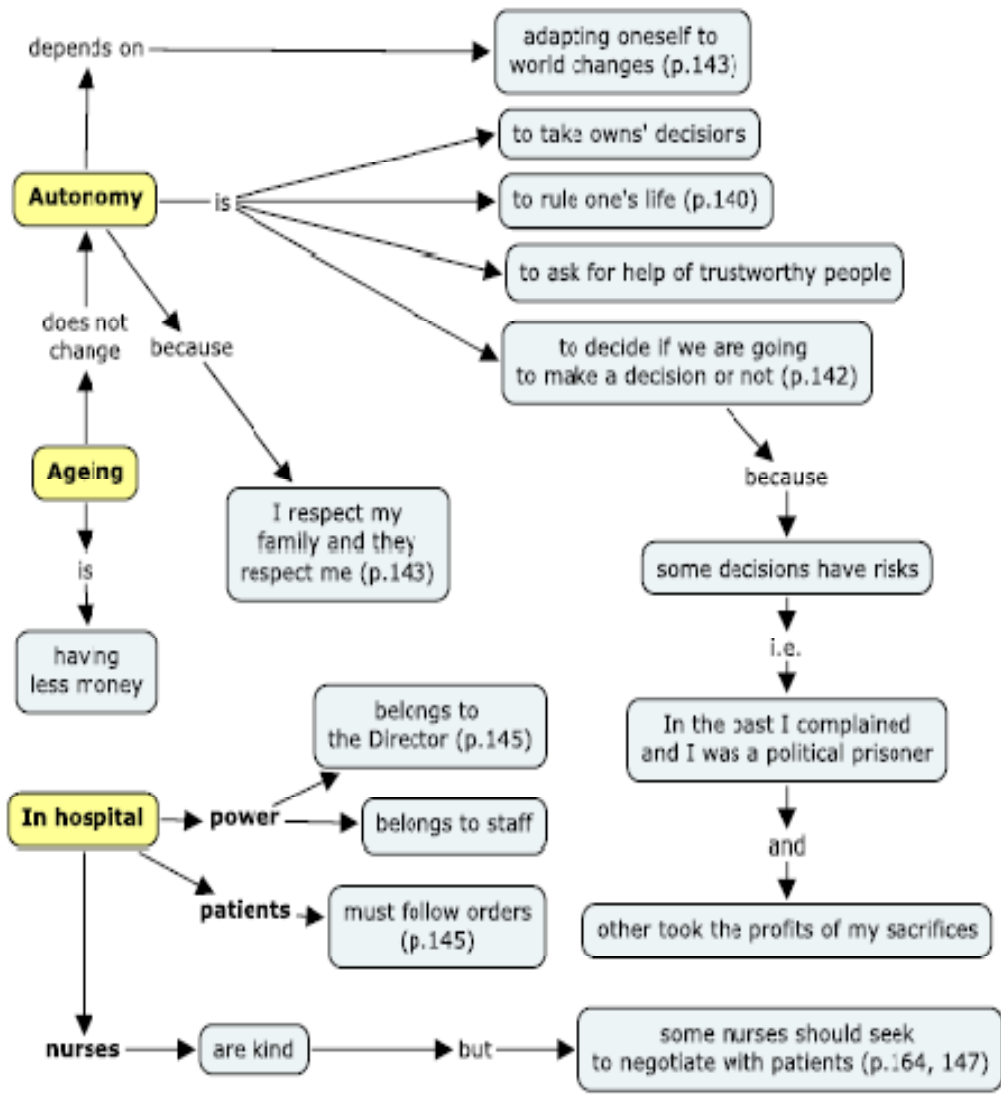


Patient_10

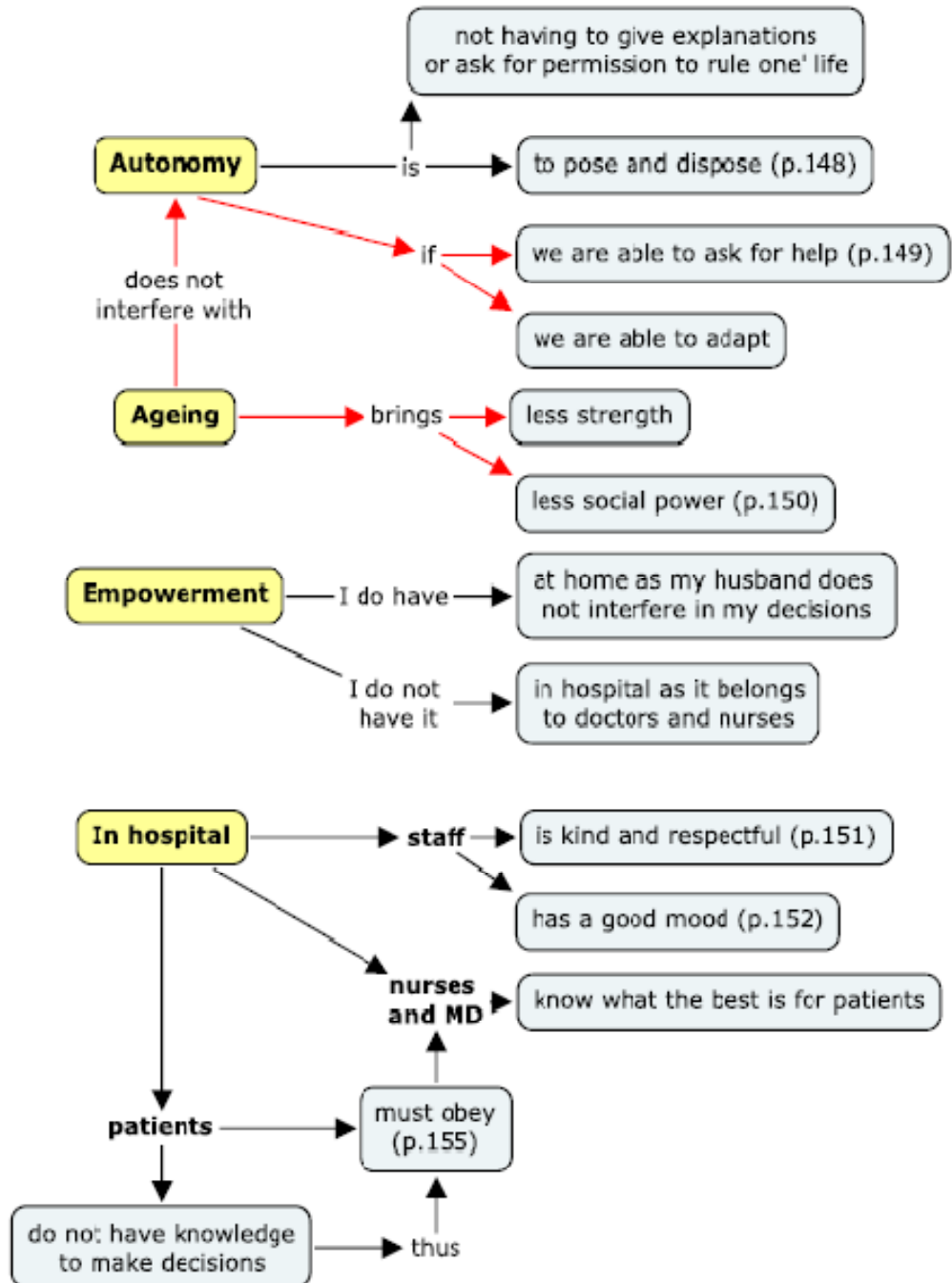




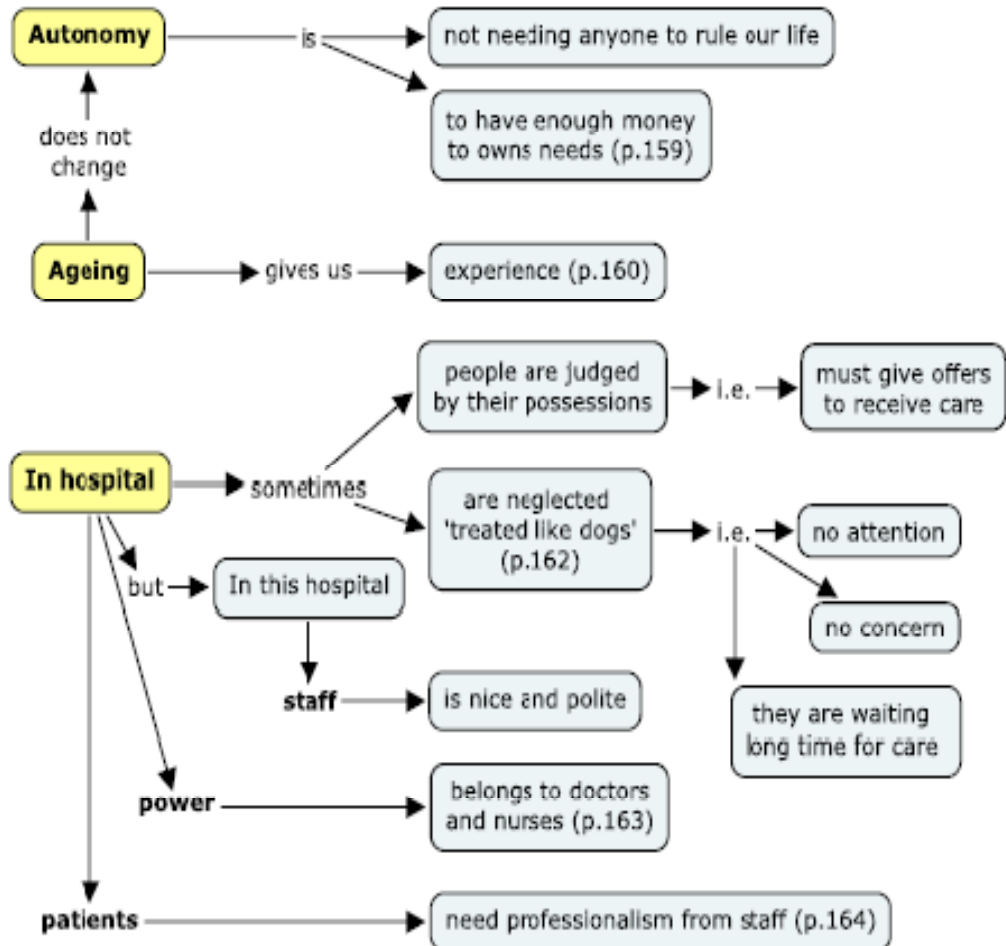
Patient_12



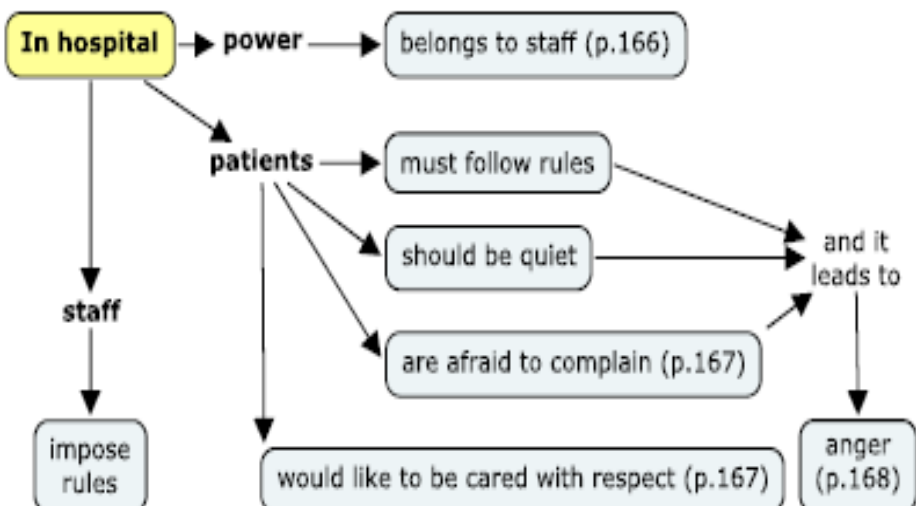
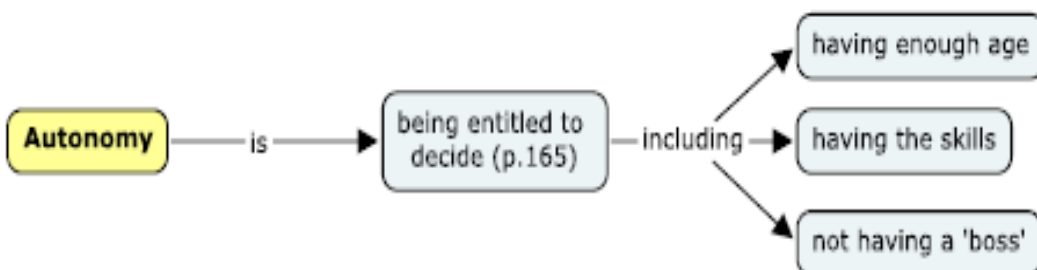
Patient_13



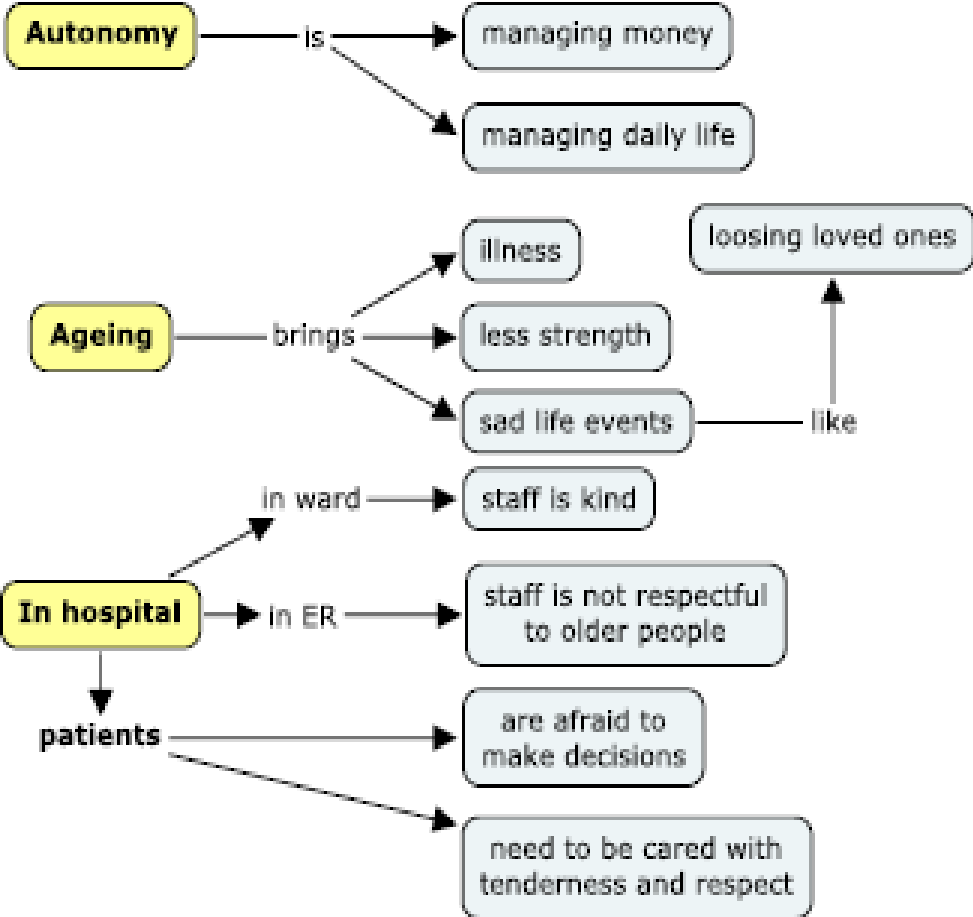
Patient_14



Patient_15



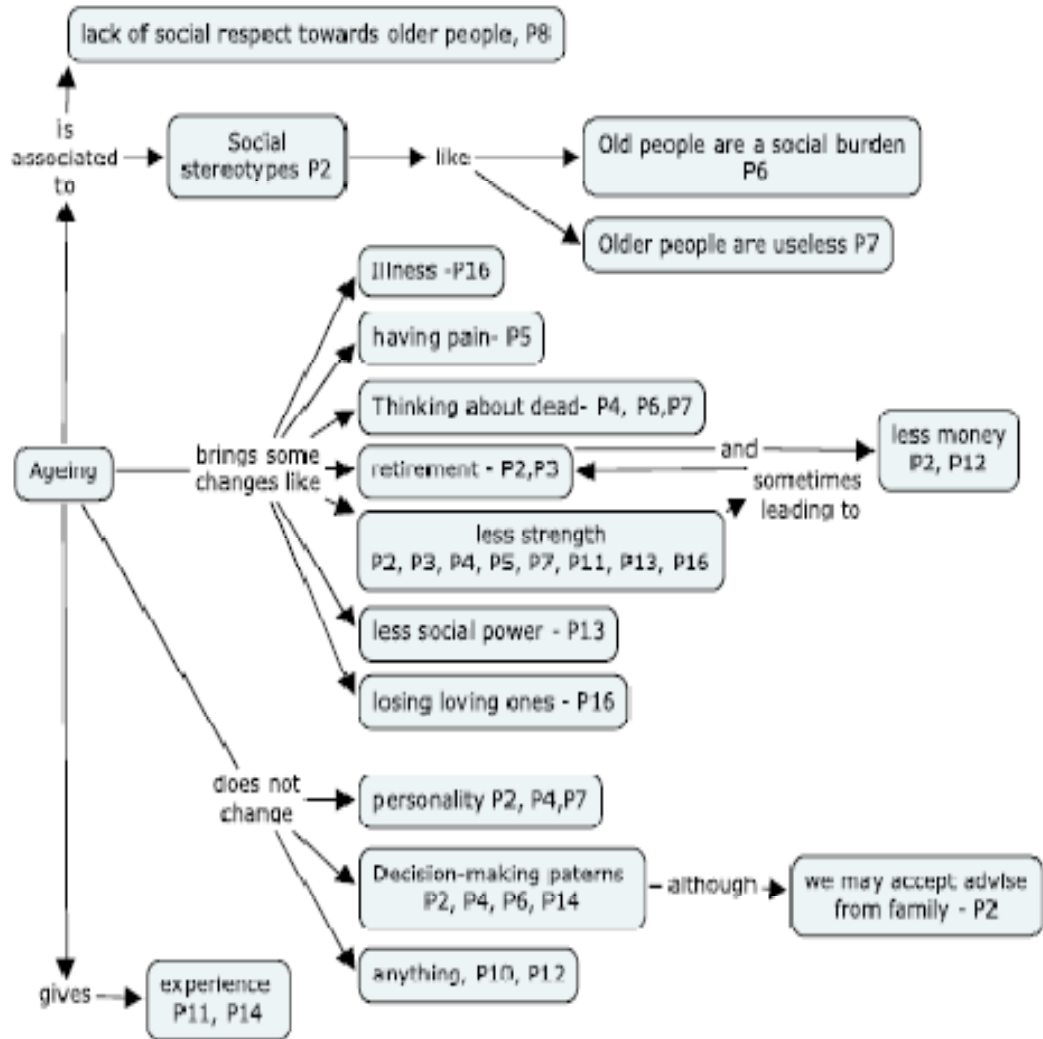
Patient_16



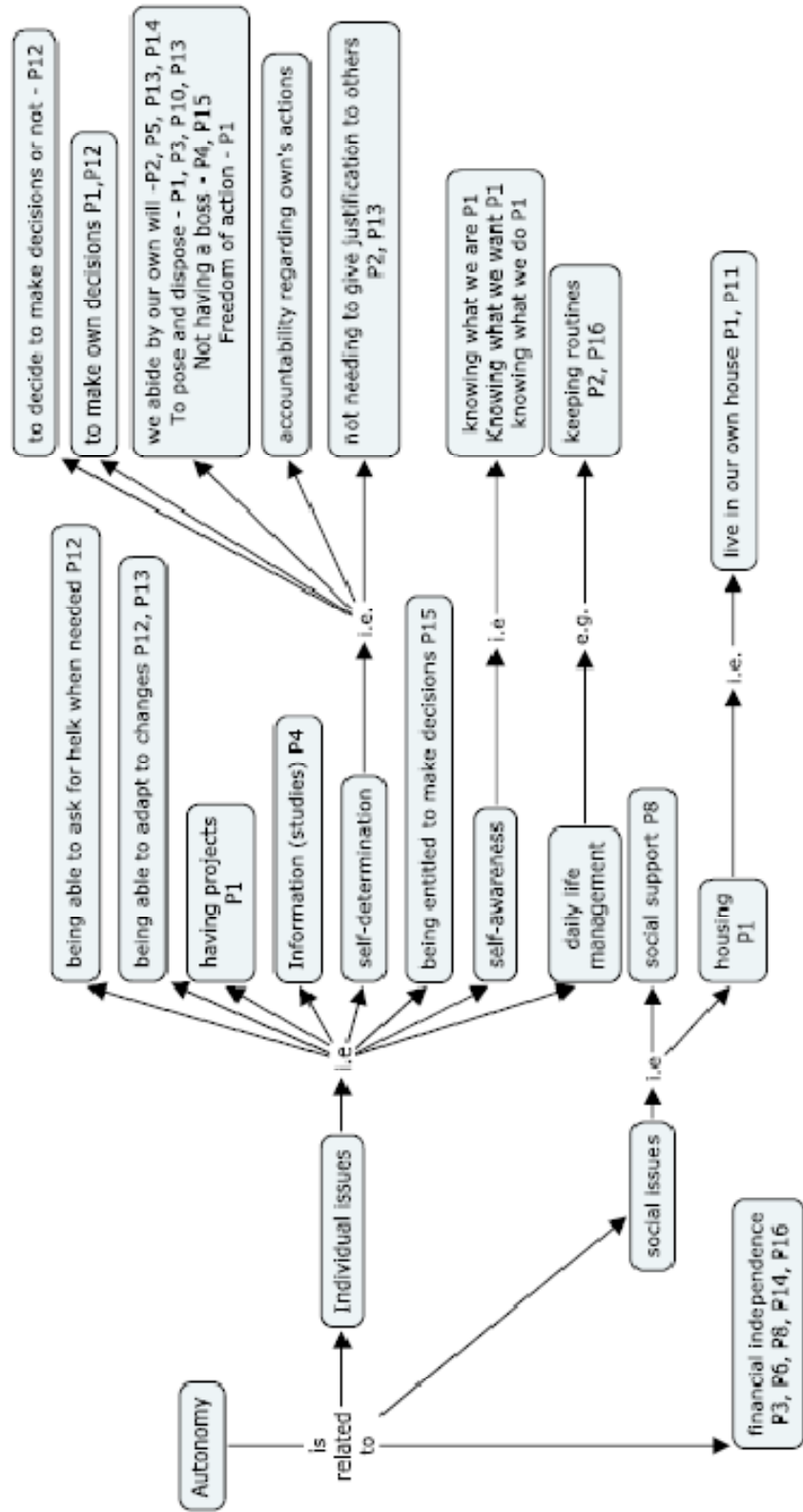
APPENDIX 22

PATIENTS' GLOBAL CONCEPTUAL MAP

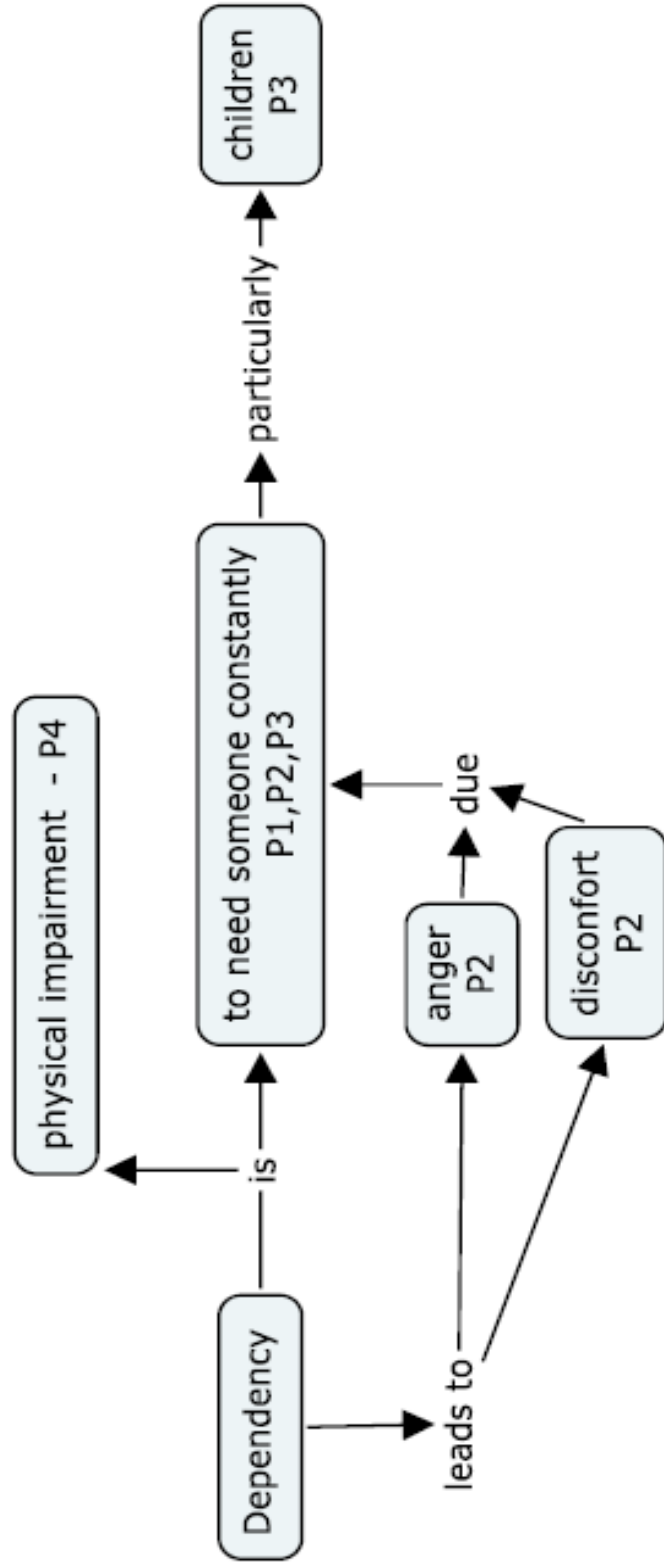
Patients' concept of ageing



Patients' concept of autonomy



Patients' concept of dependency



Patients' concept of empowerment

