

BETTER MENTAL HEALTH –
PATIENT AND CARER STUDY

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Study Aims

- What is the experience of hospitalisation from the perspectives of the person with dementia, their family caregivers, and the patients who share the ward with the person with dementia (co-patient)?
- What would improve the experience of hospitalisation from these three perspectives?

Research methodology

- Qualitative approach informed by ethnographic and grounded theory principles
- We wanted to understand the experiences of people with dementia – best uncovered 'in the field'
- Not appropriate to conduct interviews with people with dementia on hospital wards
- A key component of person-centred care is seeing the world from the perspective of the person with dementia (Brooker, 2007)

Methods

- 72 hours of non participant observation of people with dementia on acute hospital wards
- 35 interviews with family carers and patients (relating to 34 patients) following 'discharge' from hospital
- 4 interviews with co-patients

Recruitment

- All participants had been recruited during a large cohort study (part of the Medical Crises in Older People Research Programme)
- As part of consenting to the large study, participants were invited to indicate a willingness to be contacted for a follow up in-depth interview
- Co-patients were recruited on an opportunistic basis

Findings

- Core Problem
 - The admission to hospital of the person with dementia causing "disruption from the routine" to all parties
- Core Process
 - Actions from all parties to gain or give a sense of control in order to cope with the disruption from the routine.
- Outcomes
 - The immediate, short and medium term consequences of the interaction of the core problem and core processes

The importance of routine

- She's now settled, it took her two or three days, but getting her back into the old routine that she had, because with Alzheimer's they've got to stay in a routine, that's the most important thing, that's the only thing they feel comfortable with, is keeping them in a routine, so going to the hospital was out of her routine. Having all these other people bothering her, you know, again the men dressing her, which it wasn't the men's fault, it was there were no females, but yes, the stress was made worse by the Alzheimer's, and that's not the hospital's fault. But don't they have a mental ward there or something? Isn't there anybody there that is equipped to come and deal with it, or come and deal with me so we could both understand a bit better?

(Sally daughter of Victoria)

The problem with "control"...

- Many meanings to the word "control". What do we mean by a sense of control?
- The ability to:
 - ▣ control self and emotions – to hold one's emotions in check, be calm, be professional, feel safe/protected
 - ▣ influence and direct care/interactions
 - ▣ monitor, supervise, regulate and verify
 - ▣ limit or restrain unwanted activities/behaviours

Outcomes

- Immediate responses
 - ▣ Vulnerability versus integrity
- Short term
 - ▣ Quality monitoring cycles
- Long term
 - ▣ Complaints/litigation
 - ▣ Anticipation of future care/set opinions
 - ▣ Satisfaction with care

Disruption from normal routine

Core Problem

Core Problem: Disruption from normal routine

- Disruptions occurs with the hospitalization of the person-with-dementia (PWD) and results in disorder, upset, interruption, agitation, and/or discombobulation to the PWD, family carers, co-patients and the staff who care for them.
- The problem of disruption does not begin and end with admission to hospital but can be an ongoing series of setbacks which, if not resolved or at least minimized have an accumulative effect.

Disruptors

- Added complexity when physical and mental health problems interact
- Attitudes to people-with-dementia
- Limited capacity of the system to respond appropriately to the PWD.

Added complexity when physical and mental health problems interact

- Disruption for the PWD
- But my mum was terrified ... [she'd say] "I don't like it here" ... I think she was a bit bewildered when she first was there, she was sitting on the edge of the bed, didn't know why she was there, didn't know what was happening, and she certainly, every day we went, [she said] "are you coming to take me home?"

Jill daughter of Betty

Added complexity when physical and mental health problems interact

- Disruption for the co-patient
 - Well personally I think the same as everybody else in the ward, we couldn't damn well sleep, he would sort of wander around in the night and come right up to you in the bed and all the rest of it, so you know, it was just a damn... you slept two or three hours a night really, honestly.

Mike co-patient

Added complexity when physical and mental health problems interact

- Disruption for the carer
 - Well he completely changed when he was in there, completely, it sent him even more wappy than what he was when he went in. He wouldn't let you touch anything, if you went anywhere near his clothes or anything he'd scream at you, LEAVE THEM ALONE, THEY'RE MINE. And you had to... I mean he'd be wet, he'd wet his clothes and everything, and to take them home wash he'd be screaming at you... You had to sort of attract his attention while you rummaged in his cupboards to get what you wanted.

Martha wife of Ralph

Added complexity when physical and mental health problems interact

- Disruption for the staff
 - Mandy: "The main issue is time. I've spent 30 mins getting medicine down Elsie. You have to explain it all and she has her favourites so you feel pretty thick if you don't manage it"
- Auxiliary interjects, "What works one day may be totally different the next. A face fits today but no way tomorrow".

Observation

Attitude to people with dementia

- ...we were told by the doctors that people with dementia don't feel pain as much as somebody who hasn't got dementia.
- Kirsty granddaughter of Florence
- I don't think they was looking after Belinda, not just Belinda, anybody with dementia, it's not right, she was not given the correct kindness and the attention that she deserved.

Stacy sister of Belinda

Attitude to people with dementia

- ...she didn't realise she could press that, I said "press the buzzer for the nurse", she didn't realise she could press that you know. I says "don't shout, you know, press your button"...I mean she was not no bother compared to her in the next bed, oh dear...It was all the time constant that was.

Alma daughter of Patricia

Limited capacity of the system to respond appropriately to the PWD

- And maybe, I don't know whether that ward is geared up for dementia patients or whether it's just geared up for old people, certainly some people clearly had got dementia of some description because of the way they were behaving, but some people just looked poorly. So if it's a mixed ward they must have all sorts of jobs on to try to deal with everybody, you know, and maybe the staff don't differentiate between old and frail and dementia, maybe they don't know well enough to [differentiate].

Felicity wife of Edwin

Limited capacity of the system to respond appropriately to the PWD

- So basically when she went in she was very confused, we stood there for absolutely ages... I got there before lunch...and [we] did not get into the ward until half past 10 at night, and that in itself was an experience because she was very tired, very worn, and it does take it out of them.

Bernice daughter of April

Limited capacity of the system to respond appropriately to the PWD

- [We] phoned quite a bit but then it's ... always someone different, you never see the same people, they all tell you different and all they can tell you is what they look on the screen... No one knows anyone personally.

Veronica wife of Frank

- Just being kept out of the loop mainly. You're just a visitor, we're trying to put her right, you will get to know when we're ready to tell you. Being kept out of the loop all the time.

Bernice daughter of April

Disruption – interaction of disruptors

- I knew there was going to be needs that she would have that were not going to be seen to ... They were obviously not trained for the mental part, it was just the physical. I saw compassion in some of the nurses, but even with their compassion ... you still know that they don't know what your mother is trying to tell them. If there was somebody there trained in dealing with people with Alzheimer's ... it would have made me feel a bit better ... knowing that the trained person would know that I would know more about my mother than they did.

Sally daughter of Victoria

Gaining or giving a sense of control in order to cope with disruption

Core process

Actions by the person with dementia

- Sense of control for themselves
 - ▣ Constructive behaviours
 - ▣ Disengaged behaviours
 - ▣ Distressed behaviours
 - ▣ Neutral behaviours
- Sense of control for the family carer
 - ▣ Expressions of concern for the family carer
 - ▣ Trying to obtain drinks for the family carer

Constructive behaviours

- He got one nurse that he thought the world of and he said "She's my favourite, she's definitely my favourite, she loves me, you know, she would do anything for me."
- Derek is fed up and tired, he is also fed up with having no working telly and his mobile phone has been locked away by the charge nurse.....this it transpires is because he phones for the ambulance in the night when he doesn't get seen quickly enough by the nurses.

Amy daughter of Ralph

Derek, ward observation

Disengaged behaviours

- She manages to yank the Venflon out with all the tape and bandage attached ... Doris then begins dismantling all her bedding and clothing. She is naked within two minutes except for her bed socks which she pulls up carefully.
- Raymond sat at this desk for about 30 minutes ... at this time there was quite a bit of cheerful chatter between the staff, patients and relatives in this bay but his body language and facial expression appeared to indicate that he was not watching or listening to it or that he was in any way interested.

Doris, ward observation

Raymond, ward observation

Distressed behaviours

- INT: So how did she cope with being in the emergency department?
- RES: Very agitated, because she talks, she goes off on a tangent ... we didn't really quite know what was going off ... [and] she didn't really know where she was anyway.
- There was a very, very disturbed patient who was shouting and screaming and you know, being very difficult ... this man was very, very disturbing, and disturbed obviously

Stacy sister of Belinda

Felicity wife of Edwin

Neutral behaviours

- He'd go into people's beds and also in the night he would say, he'd decide that something belonged to him that was by a patient's bed and then he would try to take it
- There was one woman I felt sorry for her because she was walking up and down and she said nobody wants me but she was going in the ward she was picking thing up looking. Sometimes she'd put them down then she'd perhaps walk a few steps then she'd come back and put it down again.

Mike, co-patient

Doreen, wife of Richard

Giving a sense of control to family carers

- **Expressions of concern for the family carer**
Even when I was standing next to her she'd say, "I bet your legs are really hurting you, because I couldn't stand all that time". And then she'd say to me, "Would you like to go and have a drink?"
- **Try to negotiate drinks for family carer**
They would come round with the tea trolley and that's when she used to ask um. "She's' been here ages can she have a drink?" "No sorry".

Alma daughter of Patricia

Bernice daughter of April

Actions by family carers

- Sense of control for the person with dementia
 - Countering the inadequacies of the system
 - Maintaining the personhood of person with dementia
- Sense of control for themselves
 - Promoting coping and change
 - Putting things in perspective
- Sense of control for the co-patient
 - Looking out for the co-patient
 - Keeping person with dementia occupied
- Sense of control for the member of staff
 - Supportive attitude
 - Supportive actions

Countering the inadequacies of the system

- I was trying to push everybody to get her on her feet, get her back to the care home, given they weren't going to operate or anything
Mary daughter of Gillian
- I said, "Has my granddad been to the toilet?" ... She came back and she went, "He's not opened his bowels, but that's nothing new really". And I said, "Well if any of you had really been bothered to ask me ...if my granddad don't go three times a day there's something the matter with him. My granddad is a regular bowel mover, and he's not been."

Susan granddaughter of Paul

Maintaining personhood

- The trolleys really are side by side so you really haven't got much room at all ... I stroked her hair and made sure that she was alright
Bernice, daughter of April
- I'd be concerned for people who don't have many visitors, who can't perhaps help them with their eating, and staff haven't got the time to sit by somebody and help them to eat I suppose, and that's a worry I think, and I think people with dementia need, they just need more attention I think that's the thing

Felicity niece to Bettina

Promoting coping and change

- I'm well versed, yes. I know when somebody isn't being looked after as opposed to going into hospital and being frightened ... I asked the questions ... and my mum was, "Oh you shouldn't be asking all these questions, you know. " Yes, I should, because I won't be told anything unless I ask the questions.
Jill daughter of Betty
- She doesn't complain much ... the trouble really is, because her memory's so poor that ... she couldn't tell you anyway if something had happened yesterday or even the same day ... I try and go all sort of different times of the day and ... she seems content.

Dot daughter of Jackie

Putting things in perspective

- They were approachable and I can't really complain other than, I did feel a bit concerned that I hadn't been told that she had in fact had a heart attack. But, as I say, there were no serious consequences of me not knowing.
Brenda daughter of Helen
- You just walk in and I suppose you expect to be told, but you're not are you, because they're busy. I mean my dad is the most important person in that room to me, but to them that's working there they've got everybody, not just one.

Tina daughter of Eric

Sense of control for the co-patient

- Looking out for the co-patient
 - When others were ringing and ringing and ringing for a nurse, there were none coming, you know, or you couldn't find anybody, you went to try and find them yourself
Alma daughter of Patricia
- Keeping person with dementia occupied
 - Albert was next to the window on Sidney's side, and he had a granddaughter and she was fantastic with the patients in this bay, and she said "Lets go and see if we can find some dominoes or cards, " and she went and they said, no, they'd got nothing. And she came back and she said, "I'm going to bring my own tomorrow."

Diane wife of Sidney

Supportive attitude

- I mean ... they're under pressure to get patients out, aren't they? They've got to reach the government's target, and they were making her fit the theory. And I just thought ... it's the system isn't it? It's not necessarily the staff.
Brenda daughter of Helen
- I don't know how they cope. We used to say [this] when we walked out after visiting some nights ... some of the nurses would say "Well I'm going at 7 O'clock and I'm glad!" I said I'd be glad for you as well. I felt sorry for them. It's a big responsibility.

Diane wife of Sidney

Supportive actions

- I mean the problem with him ... was that he wouldn't sit still ... he was up and down the ward walking around and I think they found this quite troubling. So if I could sit with him and try and get him to stay put that was something for them.

Felicity wife of Edwin

- [I said] "Nurse, my granddad wants a wee", "Yes, no problem I'll be one minute" ... but I said to her "If you just give it [the bottle] us, we know what to do ... we'll sort it"

Susan granddaughter of Paul

Actions by co-patients

- Sense of control for the person with dementia
 - Looking out for other patients
- Sense of control for the family carer
 - Monitoring care and reporting back
- Sense of control for the co-patient
 - Aggression
 - Being reasonable
 - Making the best of things
 - Trying to control patient behaviour
- Sense of control for the member of staff
 - Avoid blaming nurses, being reasonable

Looking out for other patients

- I said "If you want anything Mary, just call me and I'll ring my bell"

Betty, co-patient

- You had to try to do something because the nurses didn't have time, so you know people would try to gently guide him to where he should be.

Mike, co-patient

Monitoring care and reporting back

- The lady in the next bed, who was younger than me, she said to me "Your mum had to wait two and a half hours before anybody came. She'd wet the bed"
- I mean there were periods later on when she did open her eyes. Apparently one of the girls in the bed opposite said "Oh, your mum had her eyes open this morning ... she was talking"

Brenda daughter of Helen

Mary daughter of Gillian

Being reasonable

- When I went to [the] ward ... they were overstretched, they were always willing to come and help you and even though their tablets weren't taking me pain ... away, they were doing their best for me all the time

Anthony, co-patient

- You couldn't be annoyed with him because it wasn't really his fault.

Mike, co-patient

Avoid blaming nurses

- You can't say "Get out of the way" or "Move off" when you can't move. It gets a bit frustrating you know, but I'm not blaming them, they were trying to do their best for me.

Anthony, co-patient

- Sometimes they were a long while [responding to the buzzer] because I say there's not enough staff on. I mean they are probably looking after ... these other people and that.

Alice, co-patient

Actions by members of staff

- Sense of control for the person with dementia
 - ▣ Interpersonal skills with the person with dementia
 - ▣ Finding out about the person from relatives
- Sense of control for the family carer
 - ▣ Recognising their relationship with the patient
 - ▣ Offering support to family carers
- Sense of control for the co-patient
 - ▣ Pre-emptive separation of the person with dementia
- Sense of control for the member of staff
 - ▣ Embracing the personhood of the person with dementia
 - ▣ Protecting self without jeopardising personhood
 - ▣ Suspending personhood of the person with dementia

Use of interpersonal skills

- There was this big guy, male nurse. He was brilliant with her, he was. He had her in stitches, "Come on Patricia, come on I'll get you sorted". You know, he was really nice.

Alma, daughter of Patricia
- The social worker at the hospital ... was absolutely brilliant. She went to see my dad a few times, she sat and talked to him. She didn't just go in and say "Blah, blah, blah, thank you very much". She sat and listened to him and talked to him.

Tina daughter of Eric

Finding out about the person from relatives

- I phoned them to check where she was and spoke to somebody and they said "Would you mind hanging on because the admitting nurse would like to ..." That's when I filled them in about all the bits that I knew.

Dot daughter of Jackie
- Int: Did you go to hospital with him?
- Res: No, because I can't leave my husband. A neighbour if his saw him into the ambulance ... they took all the information off us that they needed and they took him.

Tina daughter of Eric

Recognising the relationship between the patient and family carer

- Some of the staff on the ward were fantastic ... They realised I was upset and they did their best to help me and help my mum.

Mary daughter of Gillian
- There was a man ... who was one of the nurses, he was very concerned about her on the day she was leaving and was very helpful, ringing us to tell us what was happening.

Felicity, niece of Bettina

Offering reassurance to family carers

- I think it was just the fact that they cared really, particularly the consultant who seemed ... very caring and sympathetic towards her frailty and the pain she was in.

Brenda daughter of Helen
- And then she said "Don't worry, we'll look after him" and she cuddled me because I think they could tell really that ... we're just a caring family and he's like our patriarch ... so she said "He'll be fine" and I said "Thank you very much"

Susan granddaughter of Paul

Embracing the personhood of the person with dementia

- He [the nurse] didn't talk to you as though you had dementia and that, or if he had he still spoke to him as a human being then, he didn't patronise him.

Marion wife of Trev
- The housekeeper goes over to Phyllis "Phyllis, now don't cry, it does you no good love. I'll make you a cup of tea. Your husband is coming soon like he always does." the housekeeper wraps both arms around Phyllis and ricks her slowly like a child, gradually slowing until the sobbing ceases.

Ward observation, Phyllis

Protecting self without jeopardising personhood

- It's sad as they were all people once ... like real minds. They all get good care on here but they do have to wait for it sometimes and I hate that.

Ward observation conversation with a member of staff

- The nurses seemed to bring everyone together and it was a case [of] ... "If you see so and so trying to get out of bed or be in distress ring your bell will you?"

Tina daughter of Eric

Suspending personhood

- At this point he was lying on his buzzer and accidentally set it off. The buzzer rang for some time, meanwhile Mr Elliott started to doze ... a nurse approached Mr Elliott's bed and switched off the buzzer without speaking to him or seeming to notice that he was lying on his buzzer.

Tim Elliott, ward observation

- The odd time they'd say like "Oh, she's been playing up you know, she's been shouting down."

Alma daughter of Patricia

The interaction between the core problem and core process

Outcomes

Immediate responses – PWD

- The patient adjacent to Derek is reluctant to be weighed. He is very disorientated ... frail and unsteady on his feet. Four members of staff approach him at once and frog march him to a set of sitting weigh scales. He is agitated and frightened, crying with tears down his face. Not one member of staff offers any comfort or reassurance. The staff nurse tuts and reprimands him for losing more weight. The tears continue ... The patient totters to his bed, blood visible around the bottom of his pyjamas. He shuffles onto the bed and blood seeps onto the bedding from his groin. He is in discomfort and tries to pull at his pad in his trousers.

Observation

Immediate response – PWD

- The curtains reveal an upright Doris in a bright cardigan with her hair combed and glasses cleaned. She is tucked neatly into crisp white sheets. "I've been rescued" says Doris
"Are you going to have a sleep now?" asks the student nurse
"No I'm off to work soon: got my shift starting" replies Doris.

Observation

Short term outcomes – PWD

- Yes, because it would have only taken no more than five minute to get her all dressed. I've dressed her for so long now, I do it, actually less then five minutes. And I talk to her when I'm doing it, tell her we're going to for a car ride, and she's really calm ... So yeah, I think they made their jobs harder, and by making their jobs harder it made it harder on my mother ... it could have been a lot easier on the nurses, a lot less time consuming for them, and easier on my mother and on me.

Sally daughter of Victoria

- I used to go and ask how she was and the nurses, one of the nurses particularly she really liked her, 'she's my favourite nurse' and she'd tell me what she'd been up to.

Alma daughter of Patricia

Long term outcomes – PWD

□ I think he was probably so relieved to get out of the hospital [laughing] that he was, you know, he felt very restricted there ... and every time I left he was trying to get out with me, and that was very upsetting. So probably he feels more at ease now in the home, than he was in the hospital, which is a good thing. So you could say in a way...

(!) That by giving him a rotten time!!

Yes. [laughing]

(!) It made the home feel better?

Yes, quite.

Felicity wife of Edwin

Immediate responses – Family carer

□ She'd gone in about nine o'clock in the morning. And I did my one observation, I mean, I don't like to be critical ... I'm not really here to knock the NHS, but I did observe that we were left sitting behind closed curtains for a very long time, and there seemed to be oodles of staff sitting behind a desk not very far away, none of whom appeared to be doing things... but nobody came to see us. I remember having to ask, I mean, neither my mother and I hadn't had anything to eat or anything to drink since nine o'clock in the morning, it was way past lunchtime, we hadn't been offered a drink or anything, eventually, they brought us a cup of tea but I hadn't had any opportunity to go and buy myself a sandwich or get anything for my mother to eat. Neither had I had any opportunity to go to the toilet because I didn't feel I could leave my mother.

Mary daughter of Gillian

Immediate response – Family carer

□ I walked in, after I'd done me hands, and I said can you tell me where Paul is, who is it, his granddaughter. Yes, no problem. And he was right next to the bay where the station is, and he was sat in bed, and he was right at the far end where the window was, so a bit stuffy, I opened the window a bit, and he seemed alright, he wasn't, you know, as he normally is, but he was alright. And I felt quite good really that he was on there and I felt quite alright leaving that day.

Susan granddaughter of Paul

Short term outcomes – Family carer

□ I don't know if I'm expecting too much, you know, because I've spent most of my adult life in America, and dealt with hospitals there, and I used to be a nurse, this is so foreign to me. I was like kind of shocked by the lack of communication to the family members... If a family member is offering to help they don't take it, maybe there's a policy that they're not allowed to take it, but nobody will tell you that. So you just don't know what to do, you're floundering, or I felt I was floundering. I had no control and that bothered me, because I've been my mother's sole carer, even at the nursing home I am, so it frustrated me.

Sally daughter of Victoria

Short term outcomes – Family carer

□ No, I didn't get involved in that at all. I just asked the question how is she, or has she lost her temper with you, and oh yes, she's done a lot of swearing and all the rest of it. I mean it wasn't a good situation for the nursing staff to be fair ... the nursing staff knew what was happening, and they were aware of everything, so everything was fine in that direction.

Vernon son of Beryl

Long term outcomes – Family carer

□ It makes me feel angry that so much money is being poured into this hospital system and it doesn't work, it really doesn't work, because the volume of people that you're taking... I've been there at every conceivable part of the day, not just with my mum, with my husband, and it's always busy; there is never a space for anyone to be able to breathe and come and say to you, this is what's happening, that's what's happening, we'll be back to you at this time. You don't know, you wait, you wait, and you wait. And that's all you do. And because you realise the doctors are under pressure, sure [you'll] go along with it. But I'm getting to the point now where I don't feel I want to go along with it anymore, I want to express my views, I want to tell them that it isn't working, and I want to tell them what a complete and utter waste of time and money it is because they haven't got the facilities to care for all of these people.

Bernice daughter of April

Long term outcomes – Family carer

- And it put me in a horrible position and particularly, I was there when the registrar was interviewing my mother once, or tending to my mother, and she asked my mother where she'd like to be. And mother said, Home, and as she said it, her face lit up and she smiled from ear to ear, I've never seen anybody, the face change like that, and it, I just felt horribly guilty, that I couldn't, you know, I just couldn't agree to this.

Mike son of Glenys

Outcomes – co-patient

- There was a very difficult patient next to us, and that was very disturbing because he was shouting you know, screaming and all that. So that was very upsetting anyway. I would have thought, come to think of it, that if that person could have been isolated you know, so that he wasn't disturbing all the other people.

Felicity wife of Edwin

Outcomes – staff

- "It's chaotic at times. I often feel out of control. When the relatives are in your face too. I go home and have to wind down before I can face my kids. And that saddens me. I have no time to talk to the aggressive ones, to find out what's it's about. I do get fed up repeating myself and do just dart away. It's how I cope. But it probably isn't right"

Observation – conversation with staff nurse

What patients and carers suggest

Making improvements

Education, Education, Education

- I'd like more trained staff coming in, so that there were more people available to get through the various procedures
- So what you really need if somebody with a mental health problem has to go into hospital they need specially trained staff to assist the nurses with the dementia aspect?

Communication, Communication, Communication

- Yes, for an elderly person with dementia or Alzheimer's, whatever they want to call it, confusion, yes, I think there ought to be somebody that does take particulars off you [the family carer].
- Yes, they should keep everybody informed, tell them what's what. Nobody likes to be fobbed off with somebody else who don't know what's really happening. They should just tell you what's what.

Location, Location, Location

- Possibly a different sort of waiting area [in the ED], which would enable the carer to be able to sit and you know, not to have to search for a chair if there's any about. And that you would be able to just be ok with that person, know that they were certainly alright to leave for a few minutes to get them a drink, and yourself as well.

Is there anything that would have made it better for you?

- We could have had a cup of tea!
- Just make the car park nearer; Free parking would be nice

Summary

- Core Problem
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- Core Process
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- Outcomes
 - ▣ The immediate, short and long term consequences of the interaction of the core problem and core processes