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What people living with MND think about dysphagia and what do they want from dysphagia-related health services?

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MND & Dysphagia: What do we know?

- Dysphagia often occurs as a result of progressive neurological conditions such as MND.
- Dysphagia is rarely the only symptom of MND.
- 70% of people with neurogenic dysphagia present with malnutrition and dehydration (Almirall, Cabre, & Clave, 2007).
- People with MND appear to adapt and compensate for the impaired ability to swallow in the early stages of dysphagia (Ball, Wright & Lewis, 2013).
- SLTs play a key role in the management of dysphagia, but should not work in isolation. Nurses are part of dysphagia team (ASHA, 2004; IASLT 2015; RCSLT, 2014).
- Professional service should consider personal values, needs, and priorities (NICE, 2016) and service user's perspective should form the core of the care process (Oliver, Borasio, & Walsh, 2006)

- However…

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What we do not know?

1.

It is unknown how people living with MND experience dysphagia.

2.

It is unknown what people living with MND want from dysphagia-related health services.

Challenges…

- How to deliver effective and patient-centred services for a person with MND and dysphagia?
- How to adapt the service as the disease progresses?
- How to support the family caregivers involved in the management of dysphagia?
- How to ensure our service reflects the needs and values of the people living with MND?

Agenda for today: research report

1. What people living with MND think about dysphagia and dysphagia - related services?

2. What simple modifications in the services currently provided could be considered based on the wishes of people living with MND?

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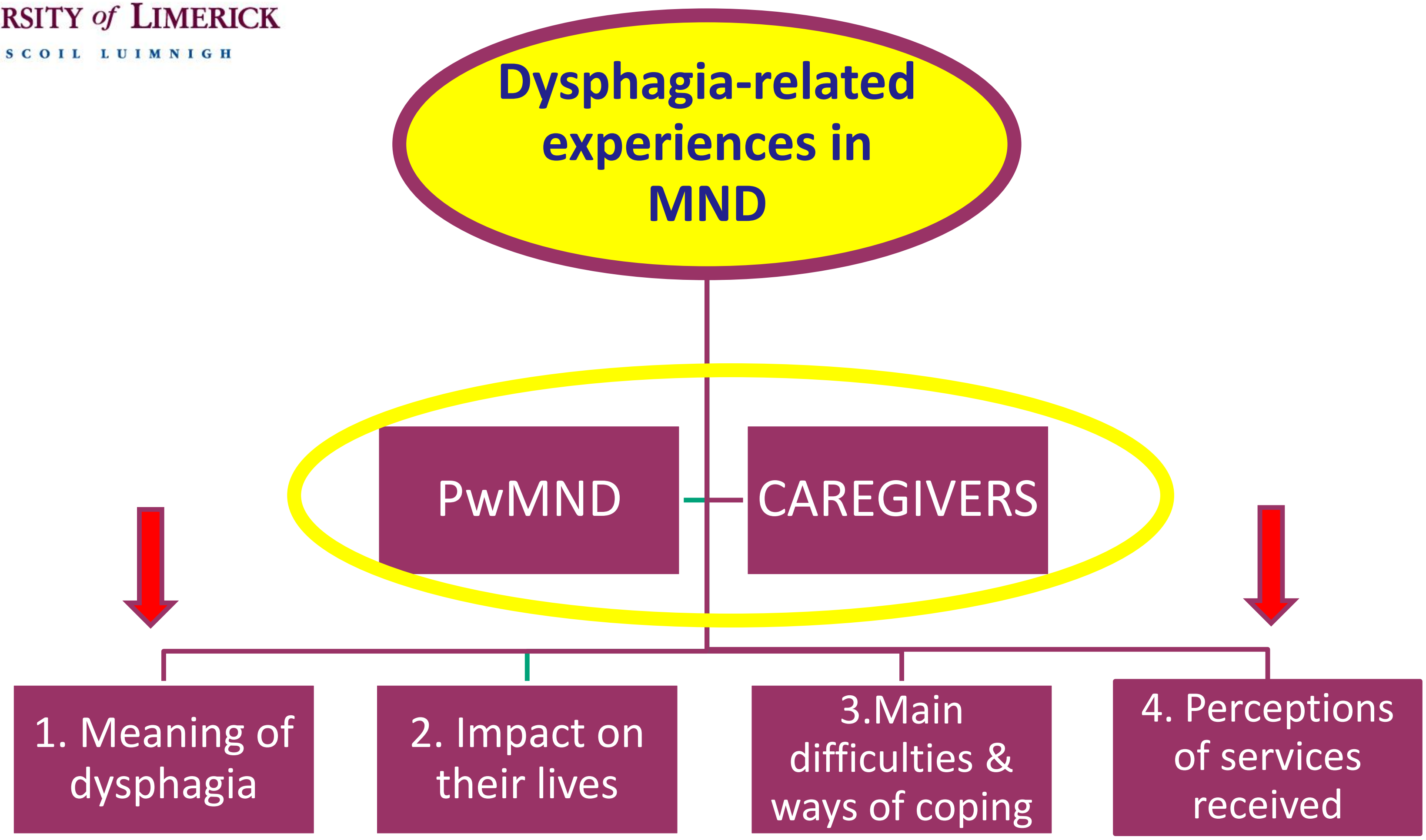
Research project



Dysphagia-related experiences in MND

PwMND

CAREGIVERS

1. Meaning of dysphagia

2. Impact on their lives

3.Main difficulties & ways of coping

4. Perceptions of services received

- Methodology: Interpretative Phenomenological Analysis (IPA)
- Method: In-depth multiple individual interviews (n = 61) and mealtime observations (n = 21)
- Participants (n=20): 10 people with MND and dysphagia and 10 caregivers from South-West of Ireland
- Data collection: 9 months

Eligibility criteria: People with MND

- Time since diagnosis (of MND and dysphagia)
- Cognitive status (Edinburgh Cognitive and Behavioural ALS Screen – ECAS, Abrahams & Bak, 2013)
- Communication ability
- Reporting changes in eating & drinking since MND: Functional Oral Intake Scale 1-5 (self-report), Crary 2005
- Age >18

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Eligibility criteria for the caregivers

- Providing regular care to a person with MND, including the care of swallowing difficulties (for example, diet preparation, supervision during meals).
- Lack of professional background in the management of dysphagia.
- Not restricted to the biological family of the person with MND.
- Age >18

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Demographic

	PwMND (n=10)	Caregivers (n=10)
Mean age	67.2 (range 55-80)	57.5 (range 37-83)
Gender	5 male, 5 female	2 male, 8 female
Employment status	8/10 retired, 2 part-time work	4 retired, 6 employed
Living area (Munster)	6 rural, 4 town, 1 city	5 rural, 5 town
Marital status	8/10 married, 1 single,1 widowed	10/10 married
Mean time post diagnosis	20 mos (range 2 mos-6 yrs)	24.5 mos (range 2 mos -7 yrs)
ALS Heath Scale (@ entry)	6 moderate, 2 severe, 2 terminal	NA
Cognitive status	9/10 normal, 1 mild* impairment	10/10 normal
Functional speech (@ entry)	5/10	NA
Relation to PwMND	NA	6 spouses, 4 offspring

Data collection – multiple interviews & observations

Sample	Face-to-face interviews	Duration	Interviews by email	Hand-written interviews
PwMND	18	31-61 min (mean 44 min)	22	4
Caregivers	15	22*-71min (mean 48 min)	2	-

Total: 44 interviews with PALS
17 interviews with the caregivers

(23 hrs 45 min of audio recordings)

Data was also collected during mealtime observations (n=21).

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Talking about dysphagia in MND…

1)

I: How is your swallowing?
Fiona: Fine. I don’t have any problem with it. (lines 76-77)

2)

I: How is your eating going? (lines 81-82)
Fiona: Great.

Can you describe your typical breakfast, lunch, and dinner?

Fiona: *Imagine unlocking something that is closed. You probably have never seen an old rat trap.*

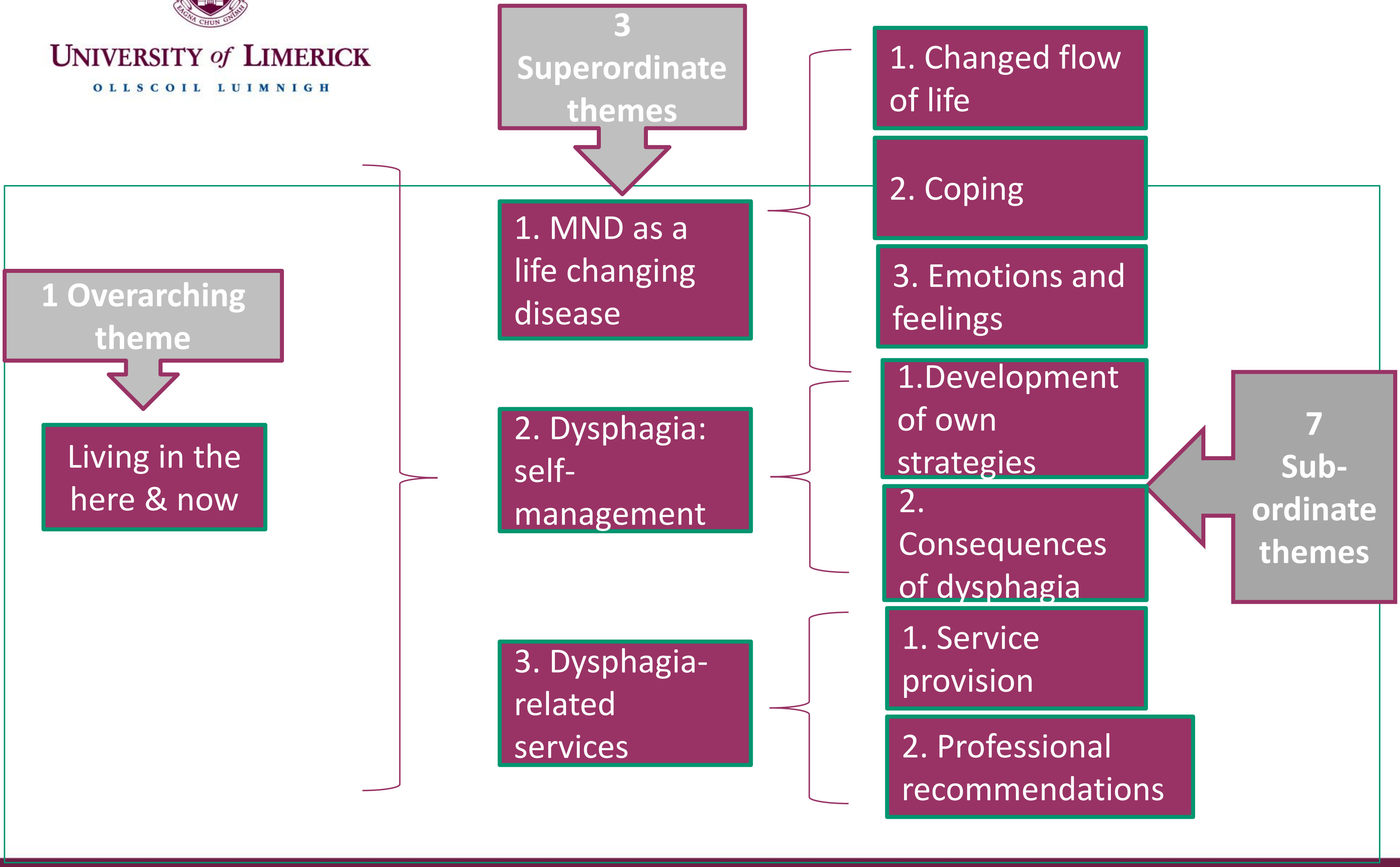
Liquids – sometimes I cough when I am not paying attention to drinking. If I am careful it is okay.

I tend to eat grapes but they run around in my mouth – extra saliva.

Apples are okay – cut into small pieces… 1,5cms.

Bread is okay. I like brown bread but have recently changed to soda bread which I toast lightly and is perfect.(…) Crust was too crumbly – it took too long to eat.

Results: PwMND



3 Superordinate themes

1 Overarching theme

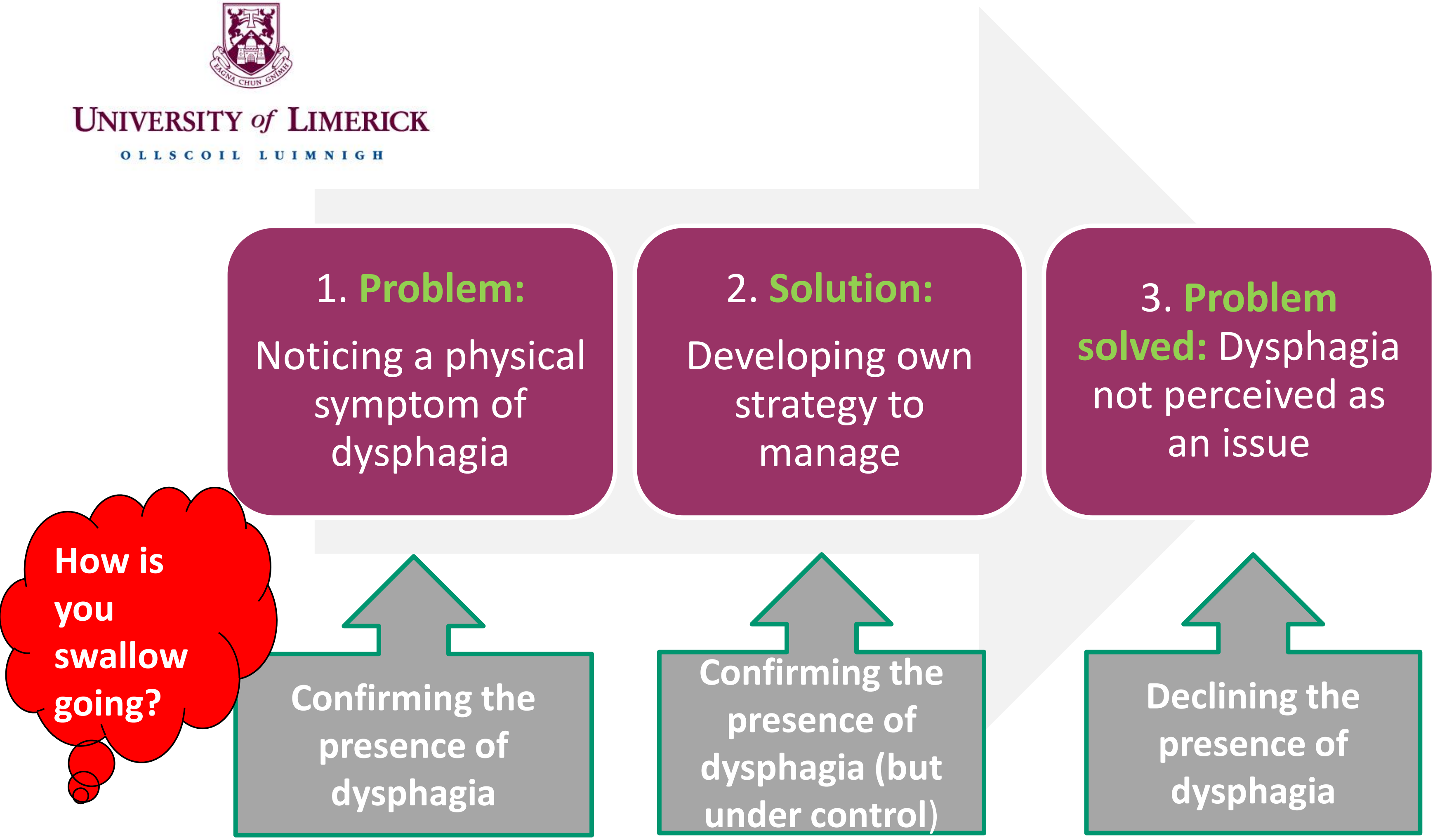
Living in the here & now

- 1. MND as a life changing disease
  - 1. Changed flow of life
  - 2. Coping
  - 3. Emotions and feelings
- 2. Dysphagia: self-management
  - 1.Development of own strategies
  - 2. Consequences of dysphagia
- 3. Dysphagia-related services
  - 1. Service provision
  - 2. Professional recommendations

7 Sub-ordinate themes

What people with MND think about dysphagia?

- Not much… unless it is severe!
- People with MND have difficulties judging their swallowing ability.
- People with MND may not report dysphagia despite noticing physical symptoms of a swallowing impairment and implementing various management techniques at home.
- People with MND are focused on developing their own strategies to manage dysphagia.
- Dysphagia is understood as an issue when people with MND find that their self-developed strategies are no longer effective OR when non-oral feeding is commenced.



How is you swallow going?

1. **Problem:** Noticing a physical symptom of dysphagia

Confirming the presence of dysphagia

2. **Solution:** Developing own strategy to manage

Confirming the presence of dysphagia (but under control)

3. **Problem solved:** Dysphagia not perceived as an issue

Declining the presence of dysphagia

General themes: Living in the here and now; Ongoing adjustment to MND; Maintaining independence

Dysphagia-related services: Overall experiences

1. General satisfaction

Eileen: *Oh A1! I couldn’t say enough about them. It’s marvellous. I think it is brilliant the back up. (…) Absolutely brilliant. I couldn’t fault a thing. (…) I feel supported a hundred percent. (…) And I see no reason to change anything, you know.*

2. However…

Dysphagia-related services: Difficulties experienced

- Clinic approach

Eileen: *Especially when the whole group are in front of you, you dread it [MND Clinic] before you go (line 508).*

Sheila: I don't like it [MND Clinics]. (…) The team are lovely. (Interviewer: There is something you don't like and I would like to know what). Looking at other people. Different stages.

Dysphagia-related services: What people with MND want?

1. **Respect.**

2. Feel **comfortable** during consultations.

3. Establish a good **rapport** with professionals.

4. To be given a choice to accept or decline a professional recommendation.

Sheila: ”[Dysphagia service] was good.(…) Depends on the person.

Interviewer: What do you think made Monica [SLT] special?

Sheila: She was at ease and made me comfortable. She was listening to me.(…) She gave advice through different stages. <u>Didn’t force</u>”

5. Hear **positives**.

Terence: *“I was pleased that she [SLT] thought I was <u>not bad</u>”*

Experiences of dysphagia: Caregivers

Slacklining - walking or balancing along a suspended length of flat webbing that is tensioned between two anchors and it bounces almost like a long and narrow trampoline.

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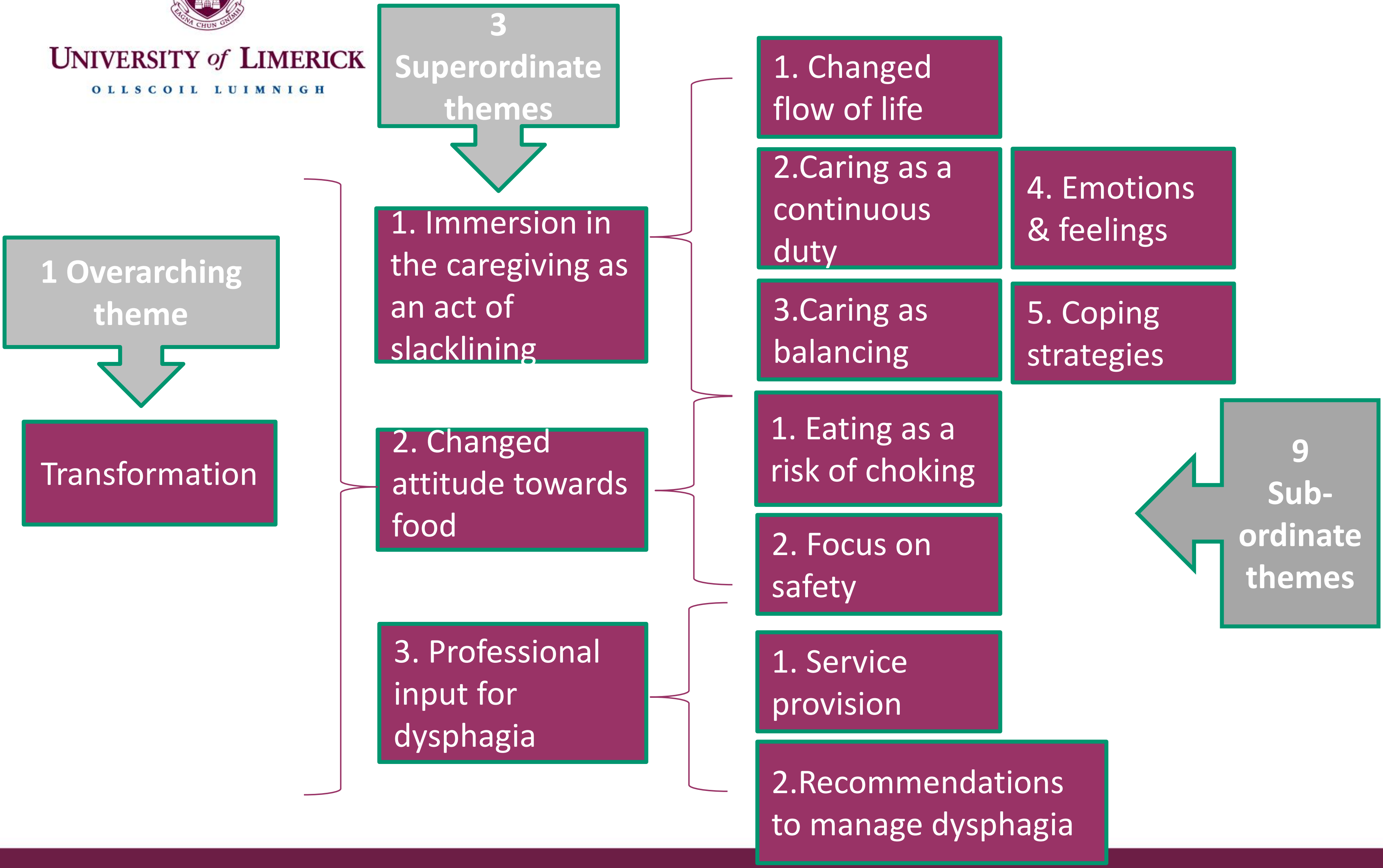
Results: Caregivers



1 Overarching theme

Transformation

3 Superordinate themes

- 1. Immersion in the caregiving as an act of slacklining
  - 1. Changed flow of life
  - 2.Caring as a continuous duty
  - 3.Caring as balancing
  - 4. Emotions & feelings
  - 5. Coping strategies
- 2. Changed attitude towards food
  - 1. Eating as a risk of choking
  - 2. Focus on safety
- 3. Professional input for dysphagia
  - 1. Service provision
  - 2.Recommendations to manage dysphagia

9 Sub-ordinate themes

What the caregivers think about dysphagia?

- It is a **visible** and **obvious problem**

Jackie: Well, they [children] can <u>see</u> that [dysphagia].(…) because Chris [husband] eats slowly number one, and number two he (…) can (…) gag on his food at times and he can get dreadful coughs trying to bring up stuff, and they can see that his dinner is soft, and that his potatoes are mashed up with butter, and they can see.

- **Food as a risk**

Kay: (…) the food was kind of lodging back along (…) you'd be kind of watching was it going down or was it staying and getting stuck.(…) She [her mother] would start coughing and coughing and coughing.

- **Eating as a struggle**

Sophia: The eating was a struggle. Anything else was no problem. He [husband] could go anywhere and we did a lot of walks along cliffs and (…) played golf and no bother. It was just the eating.

Dysphagia-related services: Problems reported

- **Timing** of intervention

Martha: Before we left we saw a speech therapist and (…) to be honest (…) I just wanted her to go away because (…)she was talking about the future and if you can't swallow, (…) you have to think about having (…) the peg feeding and all of this and I'm just like go away, you know. I just thought we don't need it, do you know? (…) I just felt that she didn't need to happen (…) at that particular time. (…) I think she could have just introduced herself if she wanted to or not even bother at all.

Dysphagia-related services: What caregivers want?

- Being offered **individual** consultations

Sophia: "I think if a partner could get to talk they [professionals] might see a different side. (…) you don't want to make it worse but you'd like to give the truth. (…) Well you won't get to the next stage fast enough (…) if you don't give the proper information. Paul [husband] may not have had the peg maybe (…) if [SLT] was going by Paul. They'd think he was fine, you know. (…) whereas he would have been loosing weight.

- Respect the **personal values** and **QOL** considerations

Una: No offence to Adam [physiotherapist] but the day he came I went oh now here, enough. Because it was the same hammering of the powder to dad and he had a full day in [hospital] and I just felt he could do without it for one day, that bloody powder. Sorry.

- Improved **domiciliary** input

Angela: Yeah, well I mean for someone like mum no one is willing to come out, you know, no one wants to come here to see her. They want her to go (…) there. (…) You know, that even in the palliative care unit there isn't anyone like that.(…) no one will come out to see her and the way she is she doesn't want to go in, which is difficult, so she just doesn't get seen by anyone really.

Final reflections…

- Dysphagia as part of MND may be experienced differently than in other populations.
- Dysphagia as part of MND should not be managed in isolation.
- Dysphagia may not be perceived as a priority.
- People with MND may deny dysphagia.
- People with MND may perceive and approach dysphagia differently to their caregivers.
- People with MND and their caregivers may have different expectations from dysphagia-related services.
- The caregivers may wish to be seen individually.
- Both people with MND and their caregivers value having a good rapport with professionals involved in their care.

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THANK YOU

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