High-consequence infectious diseases: guidance for healthcare professionals, patients and relatives

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Introduction

- Care for patients with **high-consequence infectious diseases** (HCID) with a high mortality rate is challenging.
- Highly trained healthcare professionals (HCP) provide **complex and safe care** in a **high-level isolation unit** under strict infection prevention and control (IPC) measures.
- **Admission to an HLIU** is a profound and often **traumatic** experience for both patients and their relatives.

Objective: to develop an evidence-based manual for HCP to safely guide HLIU-admitted patients and their relatives

Methods

Interviews

- Semi-structured **interviews** with patients and their relatives.
- **Transcription** and **coding** of interviews using Atlas.ti, followed by thematic analysis.
- Identification of **relevant themes**.

Focus group discussion

- **Focus group discussion** with experts based on interview results.
- Identification of **possibilities** and safe **solutions**.

Living lab

- Test possible solutions in **living lab**: feasibility, compliance, safety.
- If necessary, **improve** procedures.

Manual

- Develop evidence-based **manual** and test with end-users.
- Distribute and **disseminate** manual.

Results

May – July 2024

- 8 participants **interviewed**
- 4 **relevant themes** identified

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Theme 1: patients want to feel acknowledged as a 'human being'	
Subtheme	Quote
Personal approach	"So technical, so little human." ***– relative***
Focus on staff safety	"They were a bit afraid of me at first, you could tell. […] And that they wanted to get in and out of the room as quickly as possible. They didn't want to be in the room for too long. Which I understand, but sometimes it's a bit annoying." ***– patient***
Fear among staff	"And then the doctor said that they also found it quite scary. But someone had to have contact with a family member of the patient, they couldn't get around that." ***– relative***

Theme 2: visiting restrictions	
Subtheme	Quote
Restriction of visitors on the ward	"I never fully understood why I couldn't just go there in some kind of suit and then the nurses could have kept their distance from me, and I could have just seen my family member through the window." ***– relative*** **(high-risk)**
Restriction of visitors in the room	***Interviewer*****:** "Did you want visitors in the room?" ***Patient*****:** "Yes. I asked for that very often. […] I was very upset when they refused it, I remember being very angry. […] When it would really help someone, maybe you could find a way to let someone visit after all?"
Privacy during visits	"You have the window, and you can talk. […] They [*the visitors*] could talk to me. […] With medical doctors standing next to you, you're not really going to say what bothers you. […] I don't really understand why they didn't just leave us alone for a while. You already have no physical contact, they can't come in, but to have everyone stand around listening to what I have to say isn't really necessary." ***– patient***
Final goodbyes	"We never saw our loved-one again. That is a very important thing. […]. They [*the staff*] told me that they were going to stop the medical equipment […]. And then I said to one of the doctors: 'Would you like to whisper in their ear that I love them so much?' They did. But of course, you want to do that yourself." ***– relative***

Theme 3: information provision
"Yeah, the moment of transport where we didn't know anything for a few hours and had to call around ourselves, asking: 'Where is he, what's being done, and are they working on something?' So, just not knowing anything." ***– relative***

Theme 4: aftercare
" 'But these [*personal items of the patient*] are important to the family.' 'No involvement, just throw them away.' And it still hurts, it's unnecessary" ***– relative***

Discussion

- **Strict IPC measures** impact how patients and relatives **experience** hospitalization to a HLIU.
- When using the manual, HCP can hopefully guide the patient's and relatives' **wishes and needs** to improve their **mental well-being**, within the safety precautions of HCID care in a HLIU.

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