

Details on characteristics of patients and their history

Medical facts

Medical facts were given in the requests for an EC and/or reported during the EC. Some characteristics of the patients and their histories were similar across cases, while others varied widely (see figure 1 for an overview). Regarding shared characteristics, all patients were female. All adolescent patients were (or had been at admission) at or below the 1st weight percentile, and all but one of the adult patients had a BMI under 14 kg/m², corresponding to **extreme underweight** as classified by the DSM 5 (48). The lowest reported BMI was 8.7 kg/m². Other characteristics varied considerably between patients, such as their **age** at the time of the EC (ranging from 13 to 67 years with a median of 22 years) and the time they had been living with AN (ranging from 1 to 35 years with a median of 9 years). **Comorbidities** were reported for nine patients. Psychiatric comorbidities included depressive episodes (e.g., EC3_2), substance use disorders (e.g., EC6_1), and personality disorders (e.g., EC1_1). Somatic comorbidities included sequels of the AN or associated treatment (e.g., chronic renal insufficiency or jaw osteonecrosis; EC9_1, EC14_1) and AN-independent conditions (e.g., blindness; EC6_1).

Most patients had already received multiple treatments (12/14 cases) including inpatient treatment (12/14 cases) and formal coercion (10/14 cases). The **effectiveness of previous treatment attempts, however, varied** between cases. Success in the form of weight gain in at least one of the previous inpatient treatments was reported in eight cases, although this was mostly not sustained after discharge (e.g., gaining 20 kg in involuntary inpatient treatment and rapidly losing it again in the six months following discharge; EC9_1). Ineffectiveness of previous treatment attempts was reported in six cases. In many cases (11/14), participants also reported that patients had deteriorated over the course of at least one previous treatment attempt (in an inpatient or outpatient setting). Eight patients had deteriorated during inpatient treatment, either losing weight (EC4_1, EC5_1, EC8_1) and/or exhibiting worsened psychological symptoms (such as increased self- and other-endangering behavior (EC7_1) or decreased motivation to recover; EC3_2). In six of these eight cases, the inpatient treatment during which the patient deteriorated had comprised coercion.

Information on **prognosis** was documented for all cases, namely the extent of acute danger to life (14/14 cases), the likelihood of substantial and sustained clinical remission (12/14 cases), and the prognosticated medium- and long-term survival (13/14 cases). Six patients were seen

as in acute danger to life. Two additional patients had been in acute danger to life in the past (e.g., EC1_1, EC7_1). The likelihood of achieving clinical remission with treatment was judged as good in two cases, but minimal to non-existent in nine cases. Regarding prognosticated medium- and long-term survival, EC participants believed that medical stabilization was possible and probable in four cases. Five patients were (only) seen as at risk for potentially life-threatening deterioration and/or complications (e.g., EC5_1) while in six other cases, EC participants anticipated a lethal outcome. In five of these cases, participants felt that this could not be averted, even with “massive intervention” (EC2_1).

Patients' wishes and decision-making capacity

Patient wishes were reported for all cases (see figure), by healthcare professionals and/or relatives. They pertained to the AN (8/14 cases), treatment including nutrition (14/14 cases), and/or living and dying (12/14 cases). Regarding their AN, patients mostly wished to not gain weight (EC4_1, EC9_1), to lose weight (EC7_1), and/or explicitly wished to keep their AN (EC7_1). One patient was ambivalent (wishing both to recover from and to keep their AN; EC3_1 and EC3_2) while three patients consistently wished to recover (e.g., EC8_1).

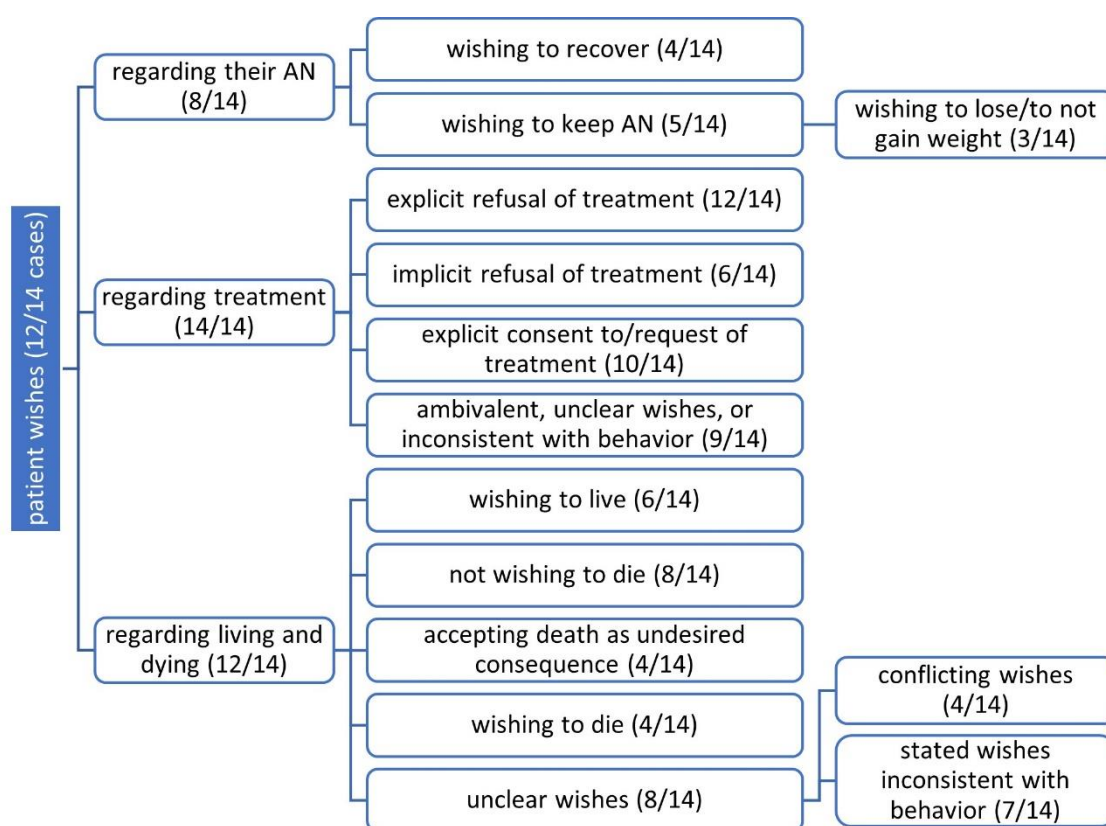


Figure. Reported patient wishes

Frequencies of wishes are presented as being present in x out of the 14 cases analyzed. AN = anorexia nervosa

Regarding current treatment, nearly all patients (13/14 cases) **refused at least one element of the treatment** that was proposed to them by their respective healthcare team, either explicitly (e.g., refusing to agree on a meal plan and refusing tube feeding; EC5_1; or refusing to be hospitalized; EC9_1) or implicitly by not cooperating (e.g., by removing a feeding tube that she had consented to have inserted; EC6_1). At the same time, most patients (10/14 cases) consented to or even requested some other treatment elements, such as consenting to feeding via NG tube (while refusing feeding via PEG tube; EC7_2) or requesting outpatient psychotherapy (while refusing inpatient treatment; EC8_1). In nine cases, patient wishes regarding treatment were reported as ambivalent, unclear, or inconsistent with behavior.

The reported **will to live** varied between patients. Eight patients were reported to wish to live on and/or not to wish to die, but to also express contradicting wishes (e.g., neither wanting to die nor wanting to live in the current state; EC1_1) and/or to exhibit contradicting behavior (e.g., refusing to gain weight when having acutely life-threatening underweight; EC4_1). Five patients were described as not wishing to die, but to accept death as undesired consequence of their treatment refusal (e.g., explicitly prioritizing not being hospitalized over staying alive, EC9_1; requesting a *do not attempt to resuscitate* order, EC12_1). One patient was reported to consistently and unambiguously express a will to live (EC13_1), and another a death wish (EC2_1).

Decision-making capacity was reported for all cases and varied between patients. Only two patients were consentaneously ascribed decision-making capacity regarding the treatment of her AN including nutrition (EC2_1 and EC13_1). In eight cases, EC participants agreed that the patient was lacking decision-making capacity regarding the treatment of their AN including nutrition. Decision-making capacity was described remained contentious or unclear in the remaining four cases. Interestingly, of the patients whose decision-making capacity regarding treatment of their AN was deemed lacking or unclear, five were reported to have retained decision-making capacity for other questions such as whom they wanted as their substitute decision maker (EC6_2) or whether they wanted to be resuscitated (EC9_1).