

A Critique of YouTube As a Data Source for the Qualitative Exploration of Patient-Reported Information on Acute Myeloid Leukemia

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BACKGROUND

- Acute myeloid leukemia (AML) is a cancer of the myeloid line of blood cells; although it is an orphan disease, it is the most common form of acute leukemia affecting adults. Elderly patients (≥ 65 years) with AML have poorer prognosis than younger patients.
- There is little published information on expectations of patients with AML regarding treatment and survival and factors influencing their treatment decision-making process.
- Patient-reported information shared on social networking websites such as YouTube™ (YouTube) provides access to unsolicited, public data available in an organic setting, which can provide valuable insights into the patient experience of a disease and its associated treatments.¹
- The Food and Drug Administration draft guidance *Patient-Focused Drug Development: Collecting Comprehensive and Representative Input* notes the usefulness of social media as a method to gain insight on the patient perspective of symptoms and disease impact.²

OBJECTIVE

- The aim of this study was to explore the feasibility of using YouTube as a data source for qualitative exploration of the patient experience of living with AML, focusing on patients with AML who are likely ineligible for intensive chemotherapy.

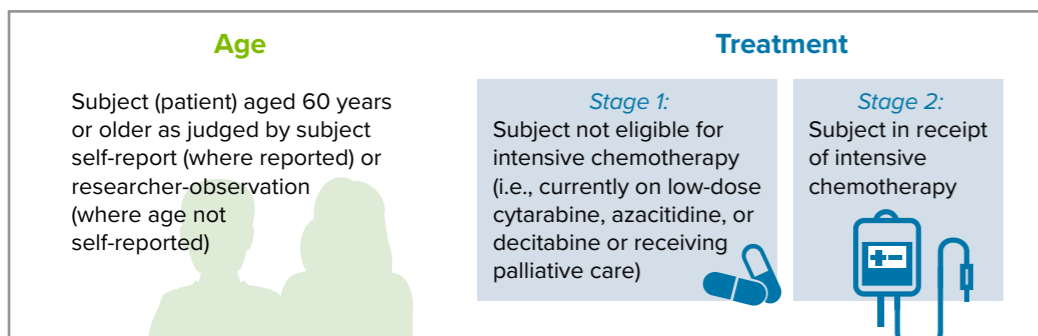
METHODS

- The study was reviewed by one of RTI International's institutional review boards, which determined that the social media review did not constitute research with human subjects (IRB study 20002015).

Data Collection

- A search of YouTube was performed, focusing on patient stories of living with AML.
- Selection criteria were based on age and treatment as described in Figure 1. Searches were conducted in two stages, with Stage 1 videos providing information on the key target patient group (chemotherapy-ineligible patients) and Stage 2 providing additional information on treatment decisions by the inclusion of patients on chemotherapy.

Figure 1. Video Selection Criteria

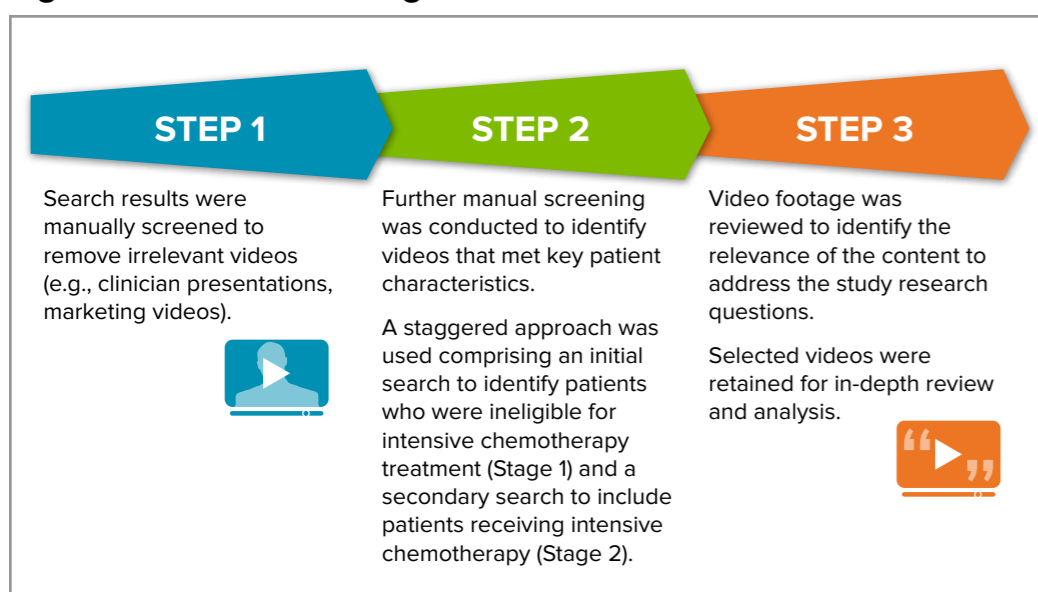


- Key search terms for the therapeutic condition and type of video were used in the search field of YouTube's website (Table 1).

Table 1. Key Search Terms

Search Area	Search Terms
Therapeutic condition	acute myeloid leukemia, AML, acute myelocytic leukemia, acute myelogenous leukemia, acute granulocytic leukemia, acute non-lymphocytic leukemia
Type of video	patient, patient story, patient narrative, patient blog, patient journey; patient diary

Figure 2. Video Screening and Review Process



Video Screening and Review

- Video screening and review was conducted in three steps (Figure 2).

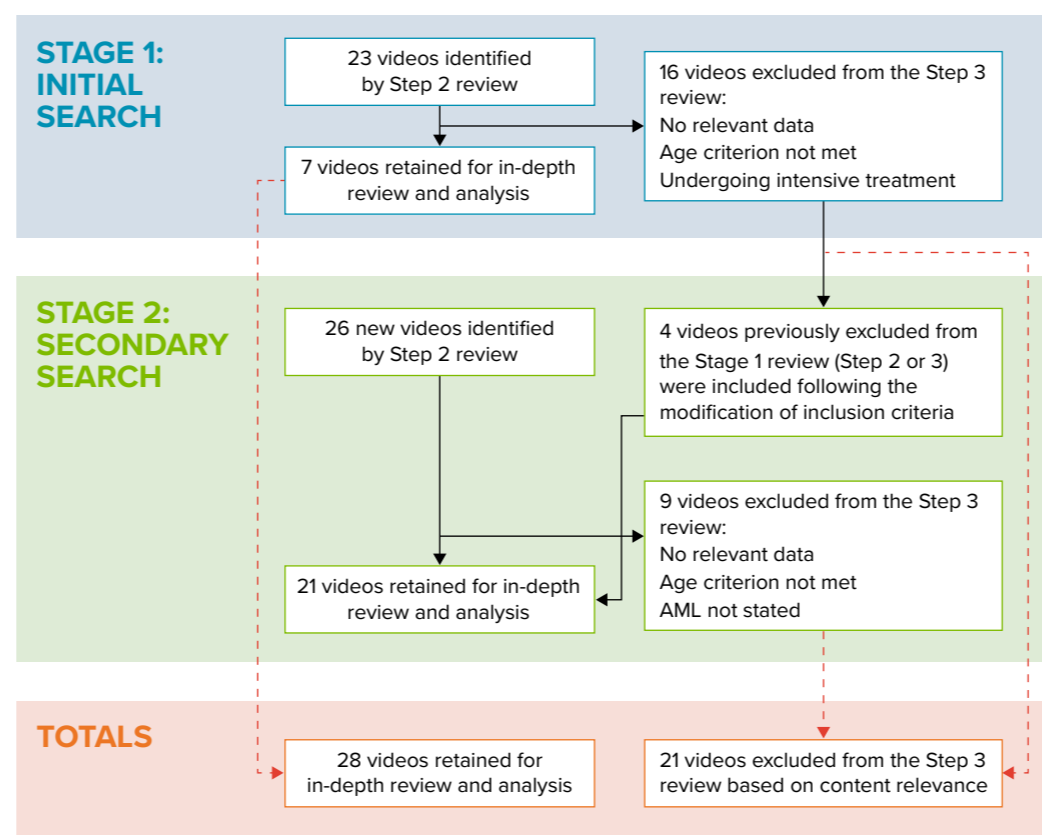
Data Analysis

- Video footage was reviewed manually by qualitative researchers.
- By using an iterative approach, the extracted raw data were analyzed thematically to identify emerging themes relevant to the study objectives.
- Demographic information (e.g., gender and age) was extracted from the video footage along with any accompanying information, as available; for some videos, the identification of approximate age and/or gender of the patient were determined by the researcher's subjective observation of the video footage.
- Where available, upload date, duration, and publisher/poster type (e.g., independent patient, medical organization, pharmaceutical company) were recorded.

RESULTS

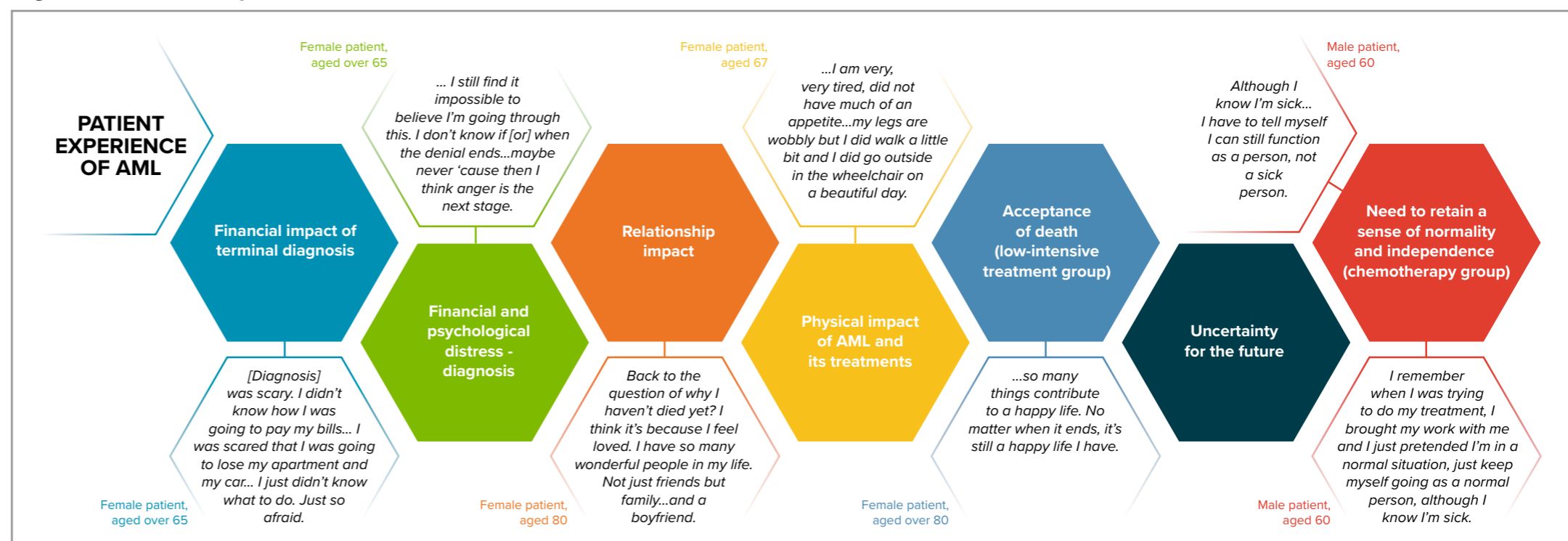
- Step 1 removed non-AML patient-specific videos (e.g., clinician presentations and marketing videos).
- Figure 3 illustrates the Step 2 staggered approach to the search and review of AML-specific patient videos posted on YouTube.

Figure 3. Staggered Approach for Searching YouTube (Step 2)



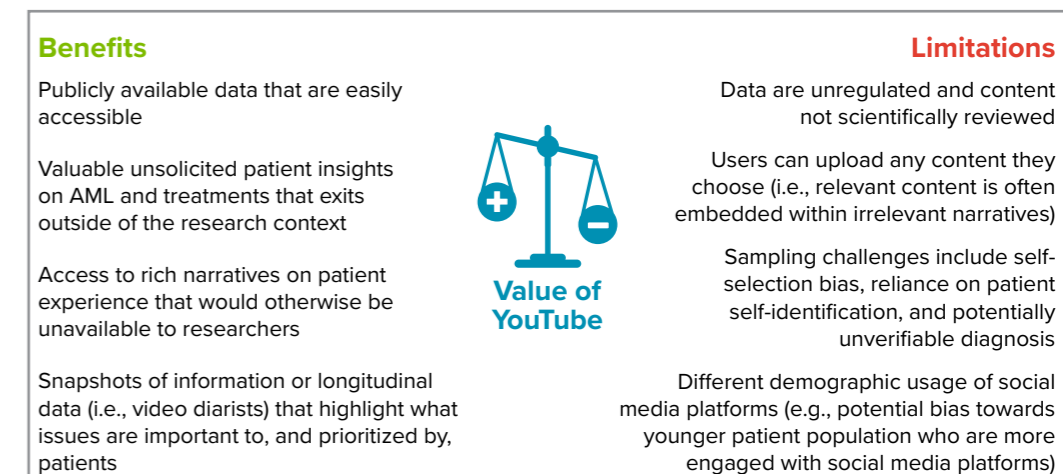
- A total of 49 videos were identified:
 - 21 were excluded due to age (patient self-report or researcher-observed < 60) or lack of relevance to study objectives.
 - 28 videos were included and reviewed in-depth. Videos were from 10 individual contributors (9 patients with AML [5 male], 1 caregiver). Patient ages ranged from 60 to 80 years.
- 75.0% of videos had been uploaded to YouTube within the past 3 years.
- 18 of the videos (64.2%) had been self-published on YouTube by the video subject (the patient); the remaining had been posted by charities/patient advocacy groups (n = 2; 7.1%), medical centers/organizations (n = 5; 17.9%), and commercial/pharmaceutical companies (n = 3; 10.7%).
- Step 3 review and analysis yielded rich information on patient experience of living with AML (Figure 4), as well as insights into key themes, including perceived benefits and challenges of living longer and perceived expectations/benefits/disadvantages to initiating/continuing treatment.

Figure 4. Patient Experience of AML



- Key drivers for treatment decisions included prior treatment experience, efficacy expectations, and anticipated daily life impacts of treatment regime.
- The value and limitations of YouTube as a data source are outlined in Figure 5.

Figure 5. Value and Limitations of YouTube



CONCLUSIONS

- This study illustrates the challenges and opportunities associated with using a social media platform such as YouTube to collect patient-reported information and demonstrates how this data source can provide valuable insights into the patient disease experience that may not be captured using traditional data-collection methods.
- Although YouTube data can yield valuable insights into the patient experience, caution is required, as the data are unregulated, and the credibility of the data can be questionable.
 - There are limitations in terms of sampling, particularly self-selection bias and reliance on patient self-identification and diagnosis, which may not be verifiable.
- Furthermore, the representativeness of the data may be challenged; the average age of a YouTube user is 18 to 24 years.³ However, groups aged 35 years and older and 55 years and older are reportedly among the fastest growing YouTube demographics.⁴
- In addition, YouTube does not allow for the implementation of a sophisticated or comprehensive search strategy, limiting the researcher to searching using simple search term combinations that may or may not identify all relevant content.

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