



Exploring the Lived Experience of a Family Member with Advanced Heart Failure: Using a Text Mining Approach

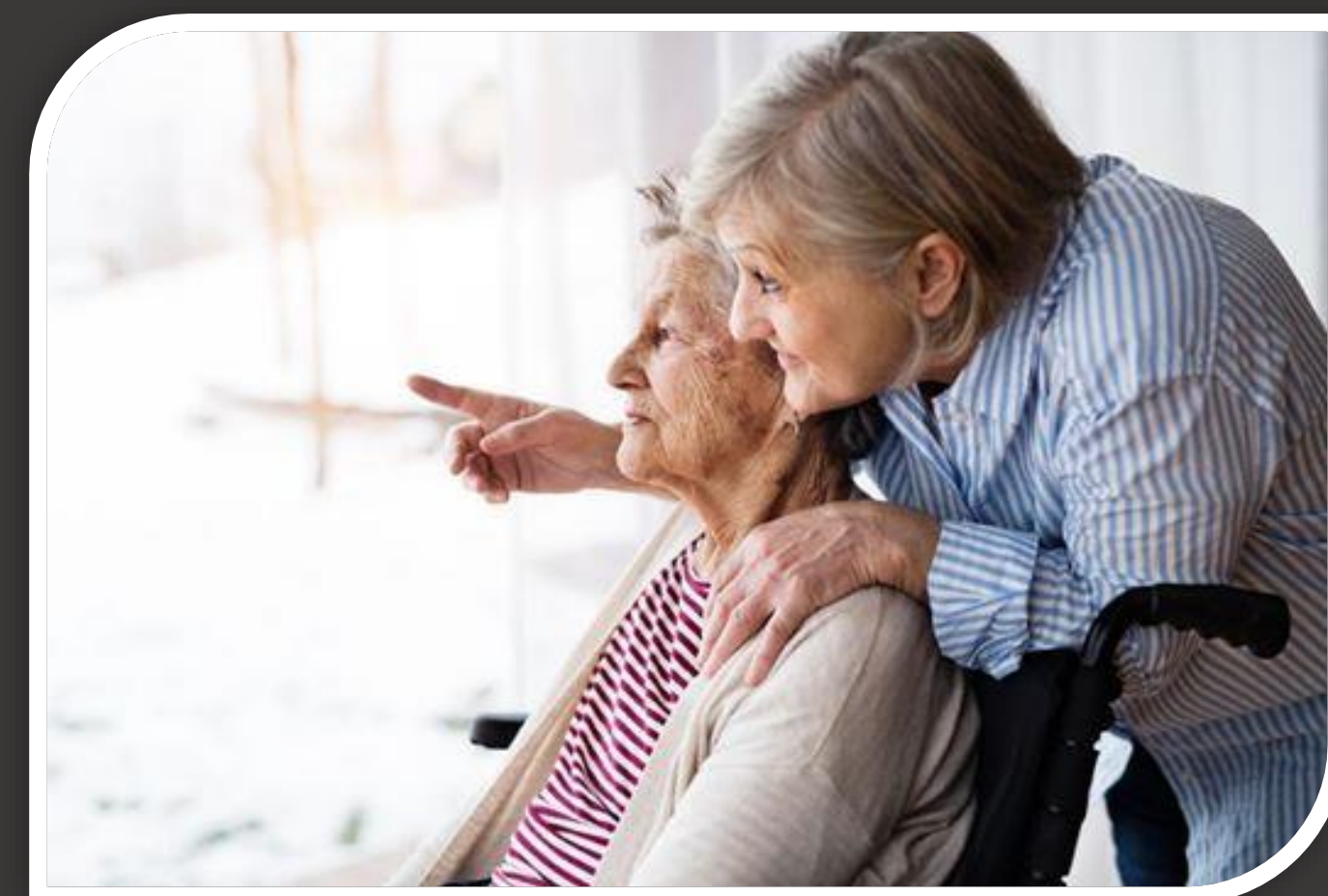
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Background

- **Heart Failure (Here after, 'HF')** has a progressive, chronic, and unpredictable trajectory of illness
- Family caregivers play a pivotal role in managing HF patients:
 - 1) Physical assistance with activities of daily living
 - 2) Symptom management
 - 3) Medication adherence
 - 4) Device monitoring (e.g., implantable cardiovascular defibrillator [ICD], left ventricular assist device [LVAD])
 - 5) Regular exercise
 - 6) Low sodium diet
- Availability of family caregivers improves the **quality of life** of patients with HF
- With the increasing prevalence of HF, **the needs of support for patients and their family caregivers are desperate**



Related Work

- **Being a family caregiver means an adaptation to new roles and changes regarding daily lives and individual well-being**
- Caregiving for a patient with terminal illness affects family members psychologically as well as physically (Bidwell, Lyons, & Lee, 2017)
- Family caregivers would experience caregiving burden, anxiety, depression, and isolation
- Family caregivers of dying people are more likely to be diagnosed with mental illness and chronic disease, and their mortality rates are higher than non-caregiving population (Grant & Graven, 2018; Gusdal et al., 2016)

Significance of the Study

1. Discovering **positive outcomes** as well as negative outcomes from caregiving can redirect the development of interventions or services for family caregivers and enrich the resources for supporting family caregivers
2. **Longitudinal qualitative data analysis** derived from the serial interviews will contribute to helping healthcare professionals understand **the changes of family caregiving experiences** across the progress of patient's illness
3. **Combining a conventional content analysis with a text mining approach** can contribute to reducing the over-simplification issues in qualitative data analysis and recovering the actual experiences and its meanings of participants

Aims of the Study

1. To investigate **the shared experiences of family caregivers** of patients with advanced HF
2. To describe **the longitudinal trajectories of advanced HF caregiving experience**
3. To explore **the patterns of family caregivers' emotional changes** across their caregiving periods

Research Design and Methods

- The original study of this secondary qualitative research was a longitudinal, qualitative descriptive study driven by grounded theory (NIH/NINR R01 NR013419)
- **100 patients with advanced HF and 102 family caregivers** were recruited and interviewed at monthly time intervals until the patients died
- The initial interview was 45-60 minutes in length followed by shorter monthly interviews of 15-20 minutes
- **In this study, the qualitative data collected from 102 family caregivers will be used**

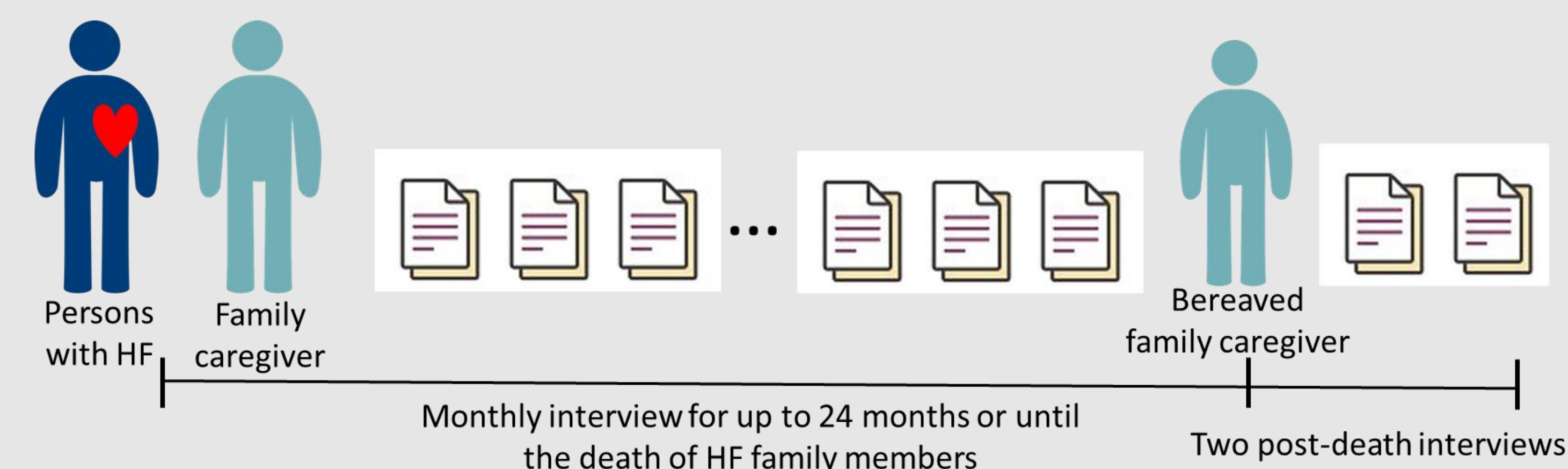


Figure 1. Data Collection

- In this proposed secondary data analysis, **LDA (latent dirichlet allocation) topic modeling** (unsupervised machine learning) will be used to elicit main themes from the huge amount of interview transcripts (Jelodar et al., 2017).
- Among the methods of topic modeling, LDA which assumes that each document and word are on a probabilistic distribution will be employed.
- To capture subjective information such as opinions, attitudes, and feelings expressed in text, **a lexicon-based method for sentiment analysis** will be used.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
1	time	turn	person	text											
2	3	1	1	(Caregiver) Can you hear me?											
3	3	1	2	Yes, I can hear you.											
4	3	1	3	Alright. This is [J] from [University]. I was just calling to check in, our monthly check in to see how things are going.											
5	3	1	4	PCS Well, not so good.											
6	3	1	5	What happened since we last talked?											
7	3	1	6	PCS Well, let me see. Was he at [Jehovah facility] the last time I spoke to you?											
8	3	1	7	He was at [Jehovah facility]. He had just been to the doctor's office and they didn't see any healing, so they sent him back for 3 m.											
9	3	1	8	PCS Right. Well, on last time we see he almost made it to his second appointment with Dr. [doctor] on March 7.											
10	3	1	9	Oh, yes.											
11	3	1	10	PCS On the 6th I guess his breathing was so bad down at [Jehovah facility] that they called in a doctor and the doctor sent him to the [J]											
12	3	1	11	Oh, me.											
13	3	1	12	PCS On Monday morning they took tests and found out that he had pneumonia and a urinary tract infection.											
14	3	1	13	Oh my goodness.											
15	3	1	14	PCS So they start giving him antibiotics and they gave him Haldol or something like that to be a sedative. So he slept all day Tuesday.											
16	3	1	15	And he was still in the hospital?											
17	3	1	16	PCS He was still in the hospital and then just this past Thursday they sent him to [nursing home]. That's where he is in the [Jehovah]											
18	3	1	17	I was just going to ask him.											

Figure 2. Feature Selection

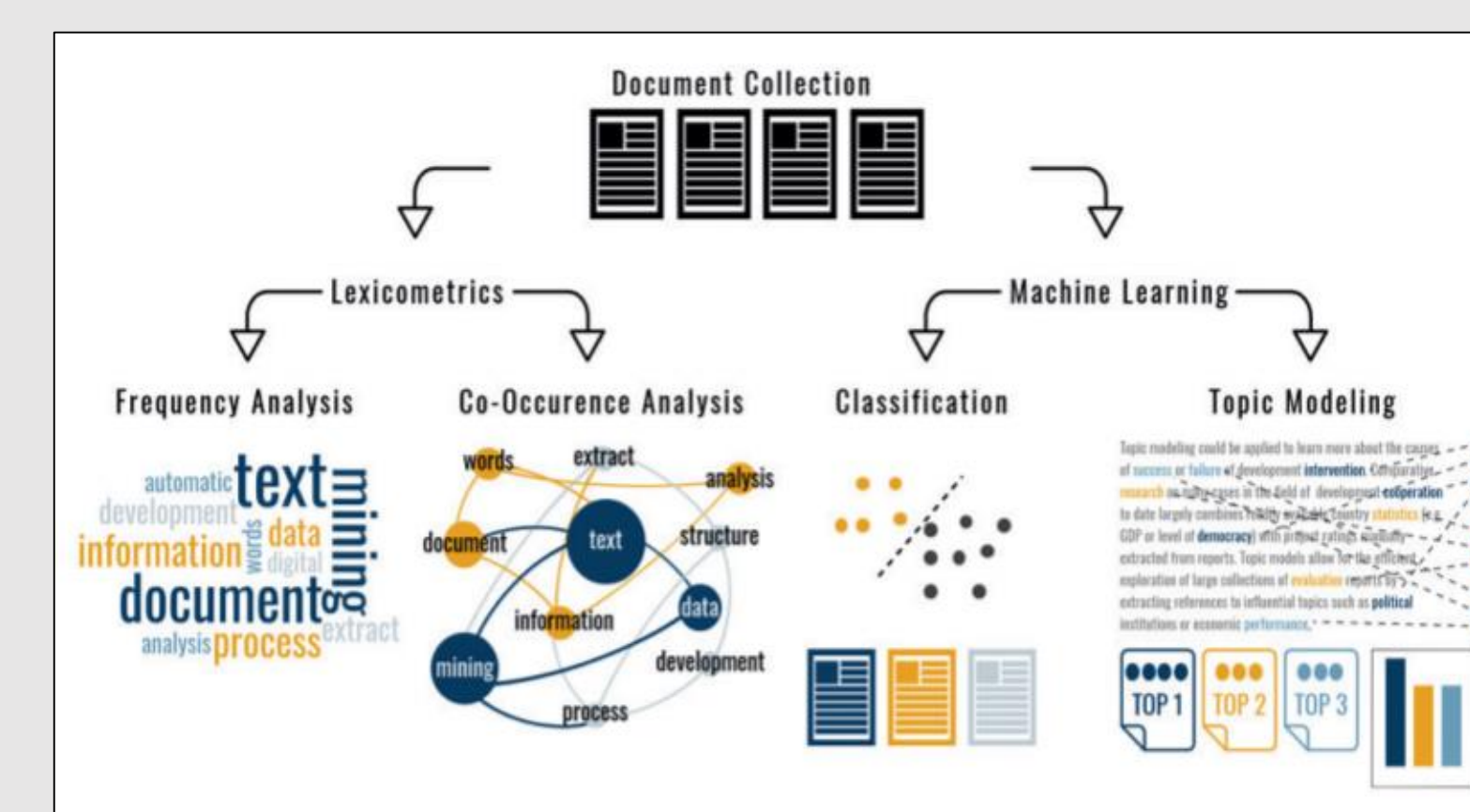


Figure 3. Conceptualization of Text Mining

- 1) **Theory and Rationale**
 - Resting upon the "Revised Stress and Coping Model" and the "Model of Caregiving Through the End of Life", the end-of-life caregiving experiences of HF family caregivers will be explored.
- 2) **Conceptualization Decisions**
 - This study will focus on family caregivers' evolving experiences of end-of-life caregiving – as they were narrated - and its meanings in a holistic manner.
- 3) **Data Sampling**
 - A subset of interview scripts of the original study will be analyzed.

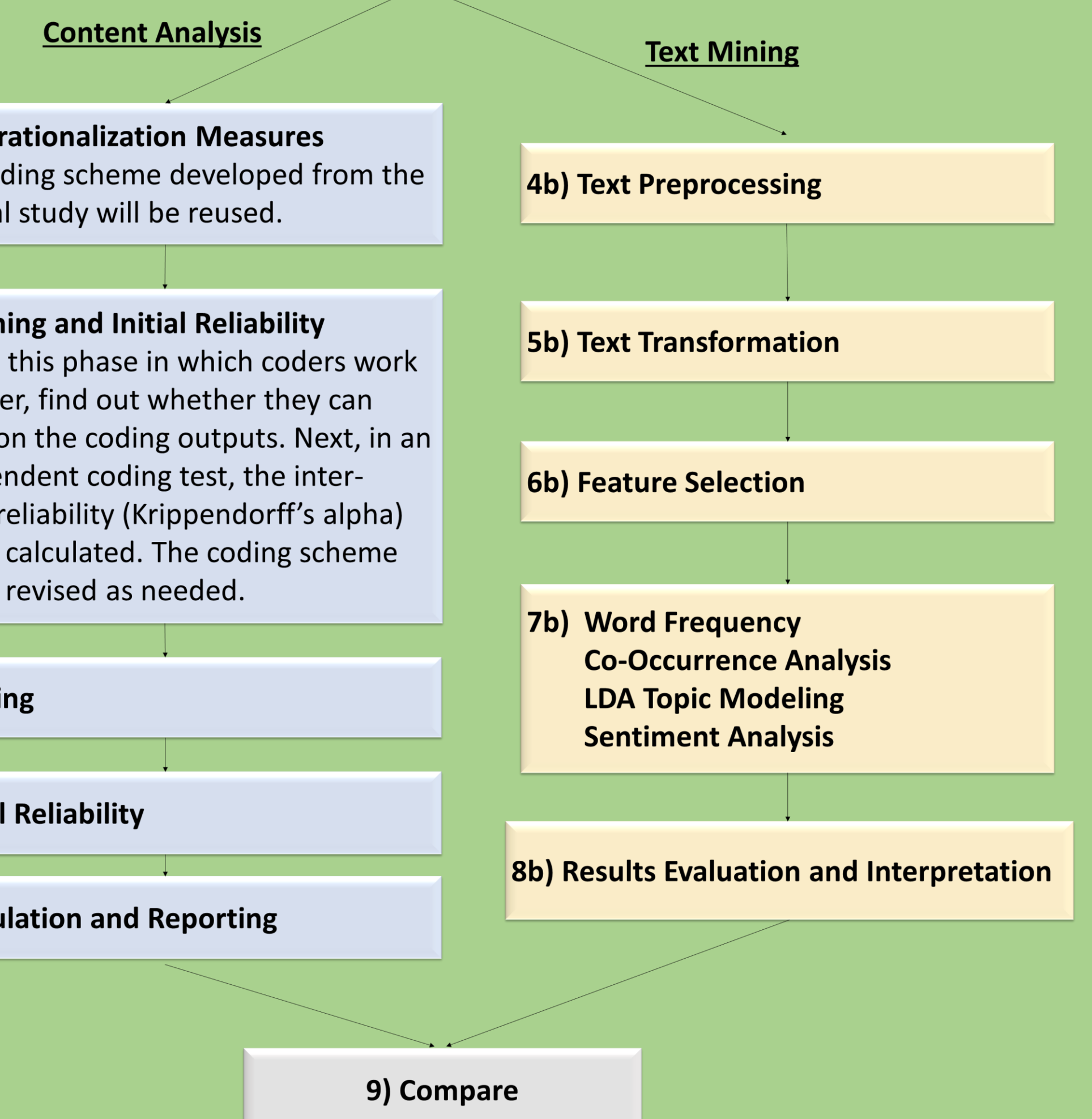


Figure 4. Overall Process of Data Analysis

References

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