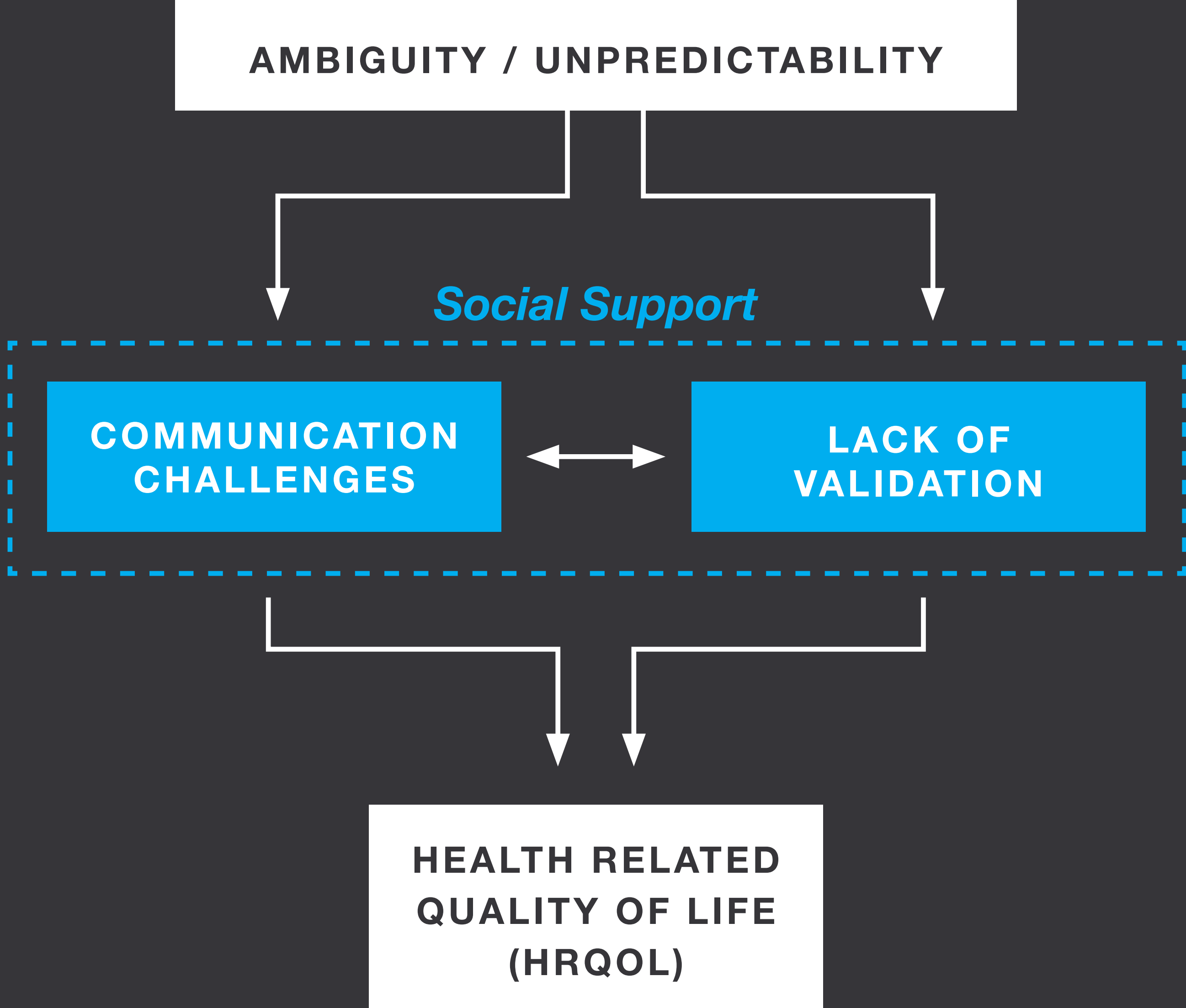


# “...Not Having the Real Support That We Need”

## Patients’ Experiences with Ambiguity of Systemic Lupus Erythematosus and Erosion of Social Support

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## Background

**Systemic lupus erythematosus (SLE)** is a chronic autoimmune disease that leads to significant morbidity and mortality and also impaired health-related quality of life (HRQOL). SLE disproportionately affects women of non-European descent, particularly African-American women, in the United States.

**Uncertainty** is a hallmark of the disease both pre- and post- diagnosis.

**Poor social support** has been identified as a determinant of persistently impaired HRQOL among individuals with SLE. However, the precise types and sources of social support

needed by individuals with SLE remains unclear. We used a **qualitative approach** to better elucidate patient experiences with SLE, focusing on barriers to quality of life. The main finding centered on respondents’ discussions of absent or deficient sources or types of social support and the consequent negative impact on their lives.

## Methods

### STUDY DESIGN

10 In depth semi-structured interviews were conducted. All interviews were audio-recorded and transcribed verbatim. Two rounds of interviews were conducted:

**First round**  
Aim: Gather information on individual history and primary barriers for individuals living with SLE.

**Second round**  
Aim: Follow-up with those interviewed on emergent themes from the first round of interviews.

### ANALYSIS

Interview transcripts were analyzed using an open-coding scheme to abstract themes. A member of the research team (JL) coded all content of the transcripts. These codes were then reviewed by two other members of the research team (EAB, AHK). Once the codes were established, the research team used inductive analysis to identify major themes based on groupings of codes.

### SAMPLING

Our study consisted of a convenience sample of 36 individuals. 13 individuals were contacted for a first-round interview, 7 of which were scheduled and completed by JL. 6 individuals were contacted for a second-round interview. 4 interviews were conducted. All participants were women, 3 out of 6 identified as African-American and 3 out of 6 identified as white.

### MEMBER-CHECKING

Findings were presented to an interactive public forum consisting of SLE patients, family members and friends of SLE patients, and health care professionals. Audience members were invited to assess findings for accuracy and credibility. This feedback was integrated into the final results.

## Results

**Ambiguity, inconsistency, and lack of symptom predictability**

“I might walk today but I may not be able to walk tomorrow. You just don’t know. It’s hit or miss...Your life is like...you don’t know. Minute by minute.”

**Communication Challenges (informational support)**

**FAMILY & FRIENDS**  
“[Other] people don’t believe that they’re [people with lupus] sick. There becomes a trust issue in a relationship.”

**PHYSICIANS**  
“...I have symptom A plus this other thing. And they [rheumatologist] said, ‘well...you’re supposed to have symptom A, B, C...’ It would just be better if they [rheumatologist] receive the information that they’re getting [but] most of them throw at me what they read...With lupus, everyone is not the same.”

**Desire for Validation (appraisal support)**

**FAMILY & FRIENDS**  
“Everybody doesn’t have the rash. I think if everybody has the rashes, every lupus person, then they [others] would believe it. But everybody doesn’t have them. It [lupus] attacks in different areas in different moments...I don’t really hang out with a lot of people. They just don’t really believe it...”

**PHYSICIANS**  
“I just break down sometime[s]. (The rheumatologist) asked me these asinine questions. But the answer I give is not good enough for (my rheumatologist). It’s not what (my rheumatologist) wants to hear...”

## Conclusion

Ambiguity of disease seems to be a primary contributor to this erosion of appraisal and informational support. Processes of appraisal and informational sources of support seem reciprocally related within informal and formal social networks, leading to distrust and erosion of network, which in turn negatively affect HRQOL. These findings begin to illuminate a potential mechanism for how poor social support negatively affects HRQOL.

## Future Directions

### INTERVENTIONS

Interventions should consider integration of physicians and informal networks members into intervention processes and capacity building in individuals with SLE to aid in rebuilding sources of informational and appraisal support. Examples may include virtual or in-person modules designed to improve general communication skills or methods of managing uncertainty/ambiguity (relaxation exercises, mindfulness, physical activity).

### FURTHER RESEARCH

Further work is needed to clarify mechanisms of social support and validate at the population level. The role of established social determinants in SLE such as race and socioeconomic status, as well as geographic variations, should also be considered in these future investigations in social support processes.

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